ANNUAL REPORT

2017-2018

The Dream We Dream Together

What are we fighting for? What do we dream of?
What would a just and hopeful future for people with M.E. look like?
If you close your eyes and imagine that future, what do you see?

At #MEAction, our vision is to create a world where all people with myalgic encephalomyelitis (ME) have support and access to compassionate and effective care.

To fulfill that vision, we're building a global, grassroots movement of people with ME, their families, and allies that leverages the power of technology, community and creativity to make meaningful change in policy, research and treatment.

To date, 40,000 people worldwide have taken at least one action with #MEAction. Together, we fight for research funding, medical education, and public awareness.

THIS YEAR'S MILESTONES:

- **Supported** #MillionsMissing events in more than 70 cities on six continents
- **Built** a coalition of 42 members of Congress to sign a bipartisan letter to the U.S. Department of Health and Human Services (HHS) in support of people with ME/CFS and advocate for the first Senate Resolution to be introduced since 1994
- **Mobilized** thousands of constituents in the UK and collaborated with Members of Parliament to initiate a series of debates attended by dozens of MPs
- **Developed** a network of over 140 Facebook groups to help strengthen our sub-communities such as military families, caregivers, LGBTQ, people of color and seniors
- **Grew** MEpedia, the #MEAction wiki encyclopedia on the science and history of ME. Its 2,000 articles have been viewed over 10 million times
- **Partnered** to create rigorous educational tools for medical practitioners
- **Created** a young scientists fellowship that we hope will inspire even more scientists to the field
- **Held** our health officials accountable, engaging the NIH, CDC and HHS in the US, and NICE in the UK

We're enormously proud of what we've accomplished but we have so much more to do. And even though our paid staff and contractors now number eight, we could do none of this without the hard work of hundreds of volunteers across the world.

This organization belongs to all of us. We thank you for your participation. Every single action you take weaves with hundreds of thousands of other actions and brings us closer to making the dream we dream together come true for all of us.

We are so looking forward to this next year with you.

PAM LAIRD,
For the Board of Directors
Volunteer Chair, Board of Directors
The Myalgic Encephalomyelytis Action Network,
a NJ non-profit corporation
Aka #MEAction

JENNIFER BREA,
For the Staff
Founder, Acting Volunteer Executive Director
The Myalgic Encephalomyelitis Action Network,
a NJ non-profit corporation

OUR VISION

To create a world where all people with myalgic encephalomyelitis (ME) have support and access to compassionate and effective care.

OUR MISSION

To build a ***global movement*** *of people with ME, their families, and allies that leverages the* ***power of technology, community*** *and* ***creativity****. Together, we fight for research funding, medical education, and public awareness.*

Our Areas of Work

We focus on five main areas:

REACH

Increase recognition of ME as a debilitating disease suffered by millions by engaging press and developing compelling multimedia educational tools.

CONNECT

Grow a thriving community of support, friendship, fun, creativity, and purpose.

ADVOCATE

Mobilize patients and allies to take action for more investment in research, public awareness, and medical education. Our emphasis is on community organizing and local action in order to build our capacity for national impact.

EDUCATE

Engage doctors, nurses, and other health professionals to encourage empathetic, knowledgeable care for all.

INSPIRE

Motivate a new generation of researchers to join this field through our outreach and fellowship programs.

ME affects an estimated 1 million Americans

On average, ME patients score more poorly on quality-of-life surveys than those with multiple sclerosis, heart failure, and various cancers.

The disease leaves 75% of those affected unable to work and 25% homebound or bedridden.

ME affects women, men and children of all ages.

ME costs the U.S. economy $17 to $24 billion a year in lost productivity and direct medical costs

ABOUT ME

2017-2018

REACH

INCREASING AWARENESS OF ME

REACH

PRESS

We worked hard to cultivate relationships with key journalists in the US and UK, and keep them informed about the latest ME news, research and developments.

In 2018, 80 press outlets wrote about the #MillionsMissing campaign and the story of ME, from local headlines in papers like *The Liverpool Echo* and the *Orlando Sentinel*, to national outlets like *the Guardian*, *BBC*, *Channel 4*, *Marie Claire*, *The Times* and *The Mighty*. Our work has also been covered in *US News & World Report*, *the Guardian Australia*, France 3, *Newsweek Espanol* and numerous **other publications**

陈明真等助阵"2019范景翔与好朋友音乐会"关怀全球ME/CFS慢性疲劳

2019年05月13日 11:47 来源：中新网上海

中新网上海新闻5月13日电 "2019 伯纳天纯ME/CFS城市慢生活中范景翔与好朋友公益音乐会"10日晚在上海梅赛德斯奔驰文化中心——音乐俱乐部举行。

Home › LIFE & STYLE › FEATURES

Out of sight, but not out of mind – The hidden victims of M.E

M.E affects people in every town in Ireland, but you might not even know they're there.

The biggest problem in dealing with hidden illnesses is that they're just that, hidden. Conditions like cancer, AIDS and others that so visibly destroy lives are easy to empathise with, and rally around.

Opinion
ME / Chronic fatigue syndrome

To the #MillionsMissing with ME/CFS, something remarkable is happening

Scott Ludlam

@ScottLudlam
Fri 11 May 2018 22.00 BST

1,791 294

As researchers close in on the
time to say to those suffering

MAY 18 2018 - 12:00AM

'I'm at my wit's end': why chronic fatigue patients are fed up

Daniella White

SHARE TWEET

Susan Hutchinson was never shy of an adventure, from climbing volcanos in Rwanda to j
the army reserves.

work 10 hours a week on her PHD
vacuuming.

der Freitag
Das Meinungsmedium

Auf eine schlimme Krankheit aufmerkam machen

#MillionsMissing ME/CFS Weltweit sind 17 Millionen, in der BRD 240.000 Menschen von dieser Krankheit betroffen. Viele können ihr Zuhause nicht mehr verlassen

asansörpress35 | Community

Teilen:

Bei diesem Beitrag handelt es sich um ein Blog aus der Freitag-Community

Können Sie sich, liebe Leserinnen und Leser, vorstellen von heute auf morgen quasi nahezu

Belle and Sebastian lead singer Stuart Murdoch opens up on 30-year battle with ME

Mark Macaskill

May 13 2018, 12:01am, The Sunday Times

REACH

UNREST HOUSE PARTIES & SCREENINGS

#MEAction organizers used *Unrest* as a tool to organize and grow our movement

They planned screenings, reached out to friends, family and elected officials, told their stories in the media, and in January of 2018, organizing over 100 house parties around the world with the help of several partner organizations.

These house parties made an impact by sparking further screenings at medical schools and the creation of new support groups, raising funds for advocacy and research, and in the U.S., resulted in a deluge phone calls demanding National Institutes of Health Director, Dr. Francis Collins, take action for people with ME.

Over the year, our community hosted more than 200 screenings around the world. Brick by brick, we are building a powerful movement of people with ME, caregivers and allies.

2017-2018

CONNECT

Growing a thriving community of support, friendship, fun, creativity, and purpose.

CONNECT

122
FACEBOOK GROUPS

18,000
MEMBERS

100,000
REACHED

Our community comprises over 122 local, state and regional and affinity Facebook groups.

Affinity groups include our men's group, LGBTQ group, youth group, seniors' group, caregivers' group, and numerous ethnic and language groups. Launched in April 2018, our largest group, Living with ME, now has 3,200 members.

Many of our groups organize regular support and advocacy calls using our Bluejeans video conferencing tool, and use Facebook to organize events, share information, support one another and take action.

This year, we organized over 125 virtual Bluejeans meetings including support groups, Christian prayer calls, listening sessions with local politicians, advocacy trainings and #MillionsMissing event planning; and initiated over 100 new groups, growing our community by a factor of 10x.

2017-2018

ADVOCATE

We mobilize patients and allies to take action for more investment in research, public awareness, and medical education.

We organize community and take action locally to build our capacity for national impact.

ADVOCATE

GLOBAL

We organized 300 #MillionsMissing visibility actions around the world demanding increased research funding for ME.

Thousands around the world used our online tools to demand change for people with ME.

34,621

PETITION SIGNATURES

2,000

CONTACTED CONGRESS

3,000

CONTACTED PARLIAMENT

ADVOCATE

UNITED STATES

We held our government officials accountable for the decisions that affect our lives and shape our futures. We fought for equitable investment in biomedical research, access to healthcare and an end to the stigma of people with ME.

The National Institutes of Health

#MillionsMissing 2018's efforts in the United States focused on demanding more investment in research from the National Institutes of Health (NIH). We sent a letter to the NIH with 7,253 signatures. In response to our demands, NIH Director Francis Collins agreed to a meeting with #MEAction on December 7, 2018. Five #MEAction representatives called on the NIH director 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.

Center for Disease Control & Prevention

We demanded changes to the CDC's ME/CFS website. We urged the CDC to make more clear the harms of graded exercise; place greater emphasis on the importance of pacing; and more accurately represent severe ME.

Federal Drug Administration

We campaigned the FDA to keep our compounded drugs legal. The FDA is in the process of reviewing bulk substances used in IV therapies, injections, and oral compounds. Even though oral or commercial versions of these substances are available, many people with ME are allergic to common fillers and require a clean, compounded version, or require a special dosage or format.

ADVOCATE

CONGRESS

We grew our capacity for Congressional, state and local advocacy, hiring a dedicated US advocacy manager. We organized meetings with Senators, members of the House of Representatives, and state legislators.

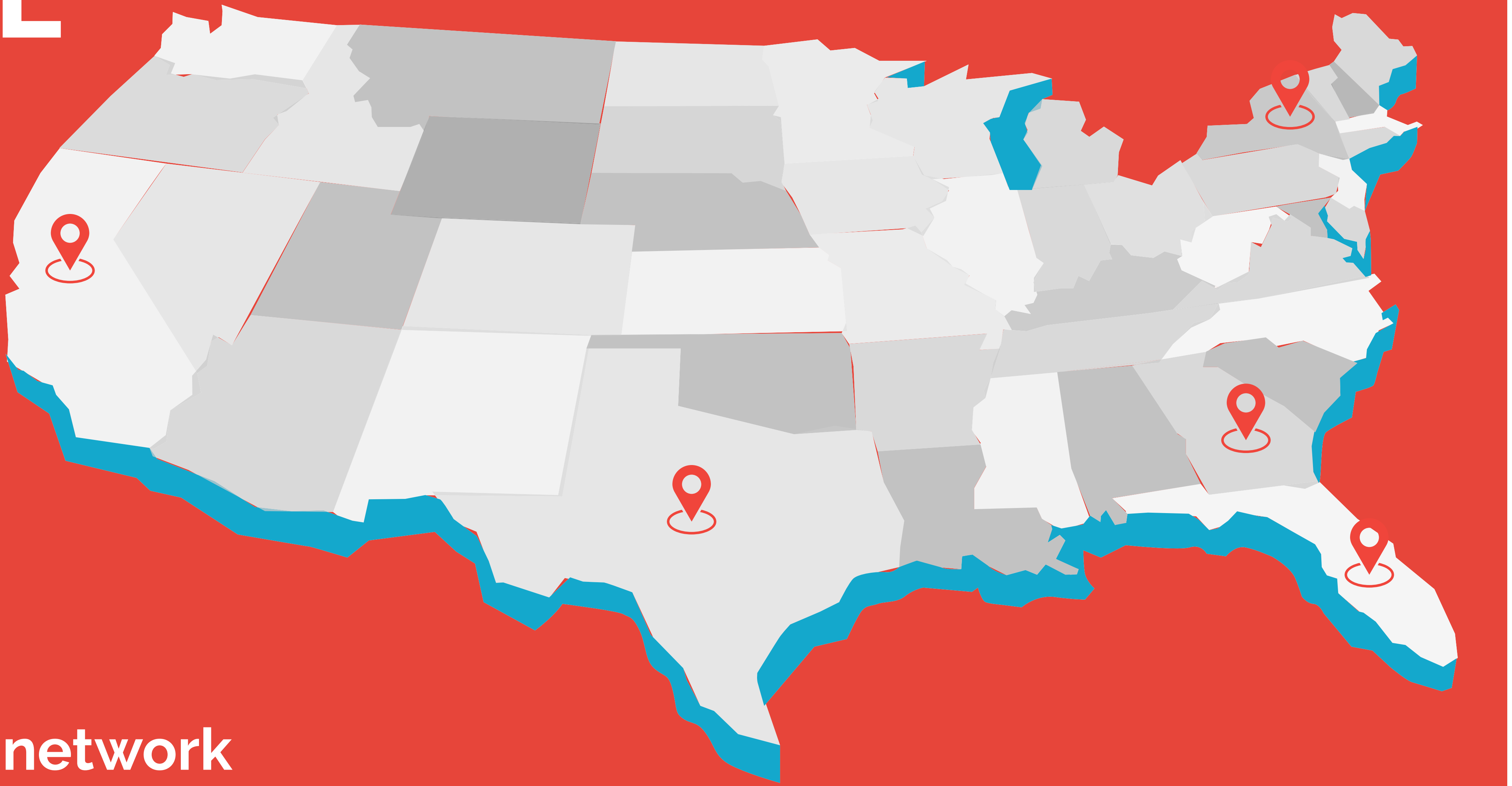
After years of advocacy work, Senators Edward Markey (D-MA), Susan Collins (R-ME), Angus King (Independent – ME) and Chris Van Hollen (D-MD) introduced S.Resolution 508 – the first ME/CFS resolution introduced since 1994. We worked in conjunction on this effort with the Solve ME/CFS Initiative and the Massachusetts ME/CFS & FM Association.

In November, #MEAction, SMCI, and eight other ME/CFS organizations sent a letter to our champions in the House of Representatives – Representatives Eshoo (CA18), Lofgren (CA19), McGovern (MA02), and Raskin (MD08) – requesting that they create legislation for ME/CFS. To our knowledge, this is the first time a coalition of this size and breadth has come together to address the needs of this severely ill and severely underserved disease community to the House of Representatives.

In December, 42 members of Congress signed a letter about ME to the Department of Health and Human Services. The bipartisan, bicameral letter – sponsored by Senator Ed Markey (MA) and Congresswoman Anna Eshoo (CA-18) – was drafted to address the sudden termination of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) and other pressing ME issues. (This letter has since taken the place of Senate Resolution 508.)

ADVOCATE

STATE & LOCAL ADVOCACY



We're building an advocacy network in all fifty states. We work with existing state organizations and grow new #MEAction state chapters in states were on-the-ground infrastructure is needed.

A network of chapters will help us more effectively reach our local communities as well as advocate for national legislation.

ADVOCATE

#MEAction New York activists worked with the New York State Department of Health to launch an ME webpage, and in New York, activists were successful in getting articles about ME published in "Family Doctor: A Journal for the NYSAFP" and in the "Monroe County Medical Society."

#MEAction New York held multiple screenings of Unrest for CME credit. One was in collaboration with the New York State Department of Health, where Health Commissioner, Dr. Howard Zucker, attended and gave opening remarks. The other was in collaboration with the New York City Department of Health where the Deputy Commissioner of Disease Control, Dr. Demetre Daskalakis, moderated.

Next, there was the New York State Senate and Assembly ME resolutions, and a listening session with New York City Council Health Chair on the needs of the community.

#MEAction Florida engaged in extensive outreach to local political offices in 2018. Even more exciting, there were a lot of people who joined in to do advocacy work for the first time! In 2019, #MEAction Florida's efforts resulted in a proclamation recognizing May 12th as Myalgic Encephalomyelitis Day in Florida, signed by Governor DeSantis.

#MEAction Texas was able to meet and personally thank Representative Beto O'Rourke for supporting and signing our ME/CFS Appropriations letter. In the summer, advocates met with Representative Michael Burgess in his district office to discuss ME/CFS clinical care needs, plus several conference calls were arranged with health legislative assistants in DC, including both Senators Cruz and Cornyn.

#MEAction Georgia began hosting two meetings (virtual) per month, one devoted to advocacy, the other devoted entirely to support. #MEAction Georgia also organized three rallies for #MillionsMissing across the state. Utilizing an app called Marco Polo, the group established support, advocacy and networking groups that greatly enhanced communication among group members.

To spread awareness in the local community, Jes Gordon partnered with The Founders improv ensemble to host an Improv Variety Show, Improv for M.E., as a fundraising event to benefit #MEAction Network and Unbarred Theater.

#MEAction California organized to speak at the University of California Regents Medical Community to request they add ME to their medical school curriculum, provide information about Continuing Medical Education on ME to their medical professionals, and partner to host a screening of *Unrest*.

ADVOCATE

UNITED KINGDOM

- We expanded our #MEAction UK team, hiring our first full-time UK coordinator for advocacy, medical education and outreach.
- We mobilized thousands of constituents in the UK and collaborated with Members of Parliament and Forward ME to initiate a series of debates attended by dozens of MPs. Forty additional MPs pledged to watch Unrest after the debates.
- #MEAction Scotland brought a 7,000 signature petition to the Scottish Parliament and ME became a part of a major party platform

ADVOCATING

IN PARLIAMENT

We worked hard to secure a three-hour **Westminster Hall debate** on Myalgic Encephalomyelitis treatment and research in June, with the cross-party support of MP Carol Monaghan (SNP) and five other MPs.

A full House of Commons debate was secured for after the New Year.

#MEAction UK and three other UK charities – ME Association, Action for ME, and the ME Trust – prepared a parliamentary briefing on ME for the debate.

The partnership originally formed after these charities expressed interest in getting involved in the “Time for Unrest” campaign following the parliamentary screening of the documentary, Unrest. These charities had also worked together to secure the first Westminster Hall debate on the PACE trial last February.

ADVOCATE

DRIVING CHANGE IN SCOTLAND

#MEAction Scotland brought a petition of 7,000 signatures to the Scottish Parliament's Petitions Committee. It called on the Scottish Government to invest in biomedical research for ME, patient care, and ME education for health professionals.

#MEAction Scotland also worked with the Scottish Liberal Democrats to pass a motion to recognize, research and educate about ME. The motion is now a part of official party policy.

ADVOCATE

ADVOCATING NICE GUIDELINES REFORM

The National Institute for Health and Care Excellence (NICE) guidelines profoundly shape the way ME is diagnosed and treated in the UK.

#MEAction UK submitted extensive formal comment on the scope of the process the guideline development committee will undertake to update its national clinical guidelines for ME. When NICE announced that it had appointed a majority of members to the ME/CFS guideline development committee who promote a psychosocial model of ME, #MEAction UK mobilized the community to demand a more balanced committee.

2017-2018

EDUCATE & INSPIRE

Educating doctors, nurses and health professionals.

Inspiring new researchers to join the field.

EDUCATE & INSPIRE

We launched the **Unrest Continuing Medical Education program**, in partnership with the American Medical Women's Association, allowing US physicians, nurses, and social workers to earn credit hours and learn about ME.

We grew **MEpedia**, our volunteer, wiki encyclopedia of the science and history of ME and related diseases. Our 2,684 articles have been viewed more than 13,840,254 times

We launched the **#MEAction Young Researcher Fellowship**, supporting the work of two promising future scientists.

#MEACTION YOUNG RESEARCHER FELLOWSHIP

#MEAction supported the work of two research assistants as part of our inaugural #MEAction Young Researcher Fellowship. The goal of the fellowship is to grow the field by supporting aspiring research scientists early in their careers, and connecting them with a lab working on ME.

This year, Paula Lara Mejia, a neuroscience major from Princeton University, and Sydney Brumfield, a neuroscience major from Wellesley College, each received $5,000 to help support their work with neuroscientist Michael VanElzakker, a researcher at Harvard Medical School. VanElzakker's work focuses on neuroinflammation in ME.

Paula and Sydney have translated their weekly readings on the neuroscience of ME/CFS into new articles for our MEpedia project.

MEET OUR VOLUNTEERS

We are deeply grateful to our volunteers. They are the lifeblood of our organization and a major driver of the impact #MEAction has had. Hundreds of activists, organizers and volunteers around the world make incredible contributions each day, in spite of often harrowing obstacles. Here are a few whose work we highlighted in 2018.

#MEACTION SCOTLAND – top row, left-to-right: Kim Gurav, Emma Shorter and Janet Sylvester (speaking) – this amazing trio organised a screening of Unrest at the Scottish Parliament that drew an audience of 70 people; organised the #MillionsMissing protest in Edinburgh, and launched a petition of 7,000 signatures calling on the Scottish Government to invest in biomedical research into ME, patient care and ME education for health professionals. **READ THEIR INTERVIEW.**

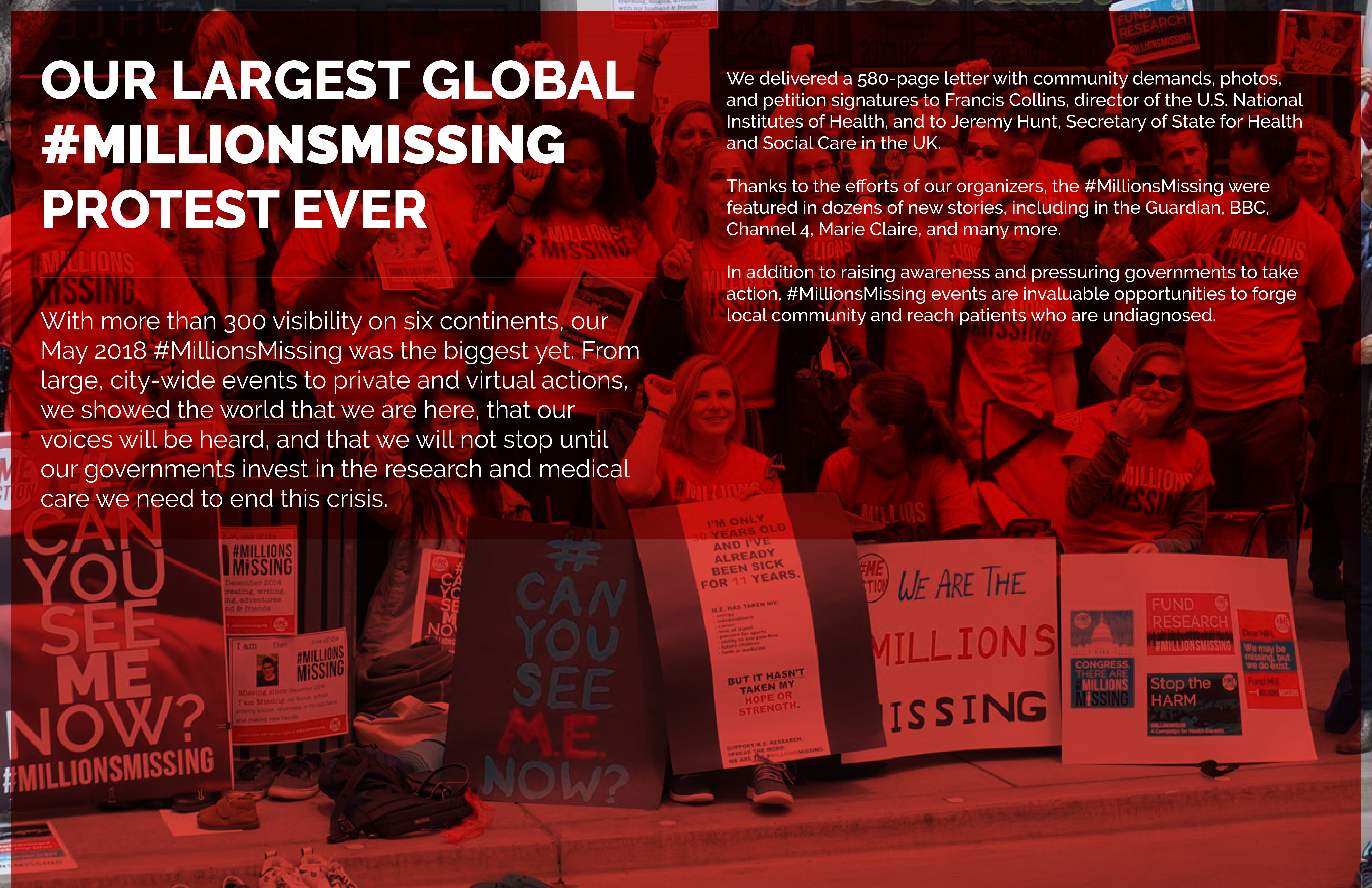
TERRI WILDER – With a background in HIV and LGBTQ rights activism, Terri has brought her experience from the AIDS movement and her passion for justice, working both from the inside and outside, to #MEAction. She has been deeply involved in the work of #MEAction New York, which has had key successes this year, including working with the state to launch a webpage about ME, and sending out a letter to over 85,000 physicians to educate them about ME. Terri was the organizer behind the crucial Per Fink protest. **READ HER INTERVIEW.**

GAIL COOPER – Co-chair of #MEAction's Congressional Advocacy Committee, Gail is one of the key players on our Congress team working to build relationships with Members of Congress that have led to important actions for our community, including the recent bipartisan letter signed by 42 representatives showing support for people with ME/CFS, sent to the HHS. **READ HER INTERVIEW.**

JENNY HORNER – Jenny first got involved in helping to launch #MEAction UK's #stopGET campaign to protect children with ME from the harms of being forced to exercise. She has also played an instrumental role in the long process of ensuring that the U.K.'s National Institute for Health and Care Excellence (NICE) updates its guidelines for ME based on the international scientific consensus and biological realities of ME. **READ HER INTERVIEW.**

SHELLEY KRAUSE – We are so thankful for the contributions of our healthy allies, like Shelley. For the past three years, Shelley has kept the community informed and updated on issues affecting people with ME through by helming our Twitter account. Shelley first made a connection to ME as a fan of the author Lauren Hillenbrand, who has ME, and then through Jennifer Brea tweeting about the desperate need for public awareness and research support back in 2014. **READ HER INTERVIEW.**

HOLLY LATHAM – We nominated Holly for her dedicated work as a social media volunteer since the inception of #MEAction. This past year, we brought her onboard as a staff member. Holly continues to volunteer her time to manage the #MEAction Tennessee Facebook Group, and the Pregnancy and Parenting with ME Facebook Group. Holly understands the painful reality of isolation from having had severe ME herself, and works hard to build online community. **READ HER INTERVIEW.**



OUR LARGEST GLOBAL #MILLIONSMISSING PROTEST EVER

With more than 300 visibility on six continents, our May 2018 #MillionsMissing was the biggest yet. From large, city-wide events to private and virtual actions, we showed the world that we are here, that our voices will be heard, and that we will not stop until our governments invest in the research and medical care we need to end this crisis.

We delivered a 580-page letter with community demands, photos, and petition signatures to Francis Collins, director of the U.S. National Institutes of Health, and to Jeremy Hunt, Secretary of State for Health and Social Care in the UK.

Thanks to the efforts of our organizers, the #MillionsMissing were featured in dozens of new stories, including in the Guardian, BBC, Channel 4, Marie Claire, 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.

#MILLIONSMISSING

Actions spanned the country, from large events in Washington DC, Minneapolis, New York, Chicago, Atlanta, Boston, Los Angeles, and San Francisco, to small but mighty actions in Eau Claire, Marietta, Morristown, Denver, and Honolulu. An #MEAction volunteer hosted a moderated virtual event to bring homebound people to together.

Annette Gaudino of Treatment Action Group, Jim Eigo of ACT UP, and actress Amy Carlson gathered at the front of Central Park in New York. Partners like Linda Tannenbaum from Open Medicine Foundation joined over 80 participants in Los Angeles, CA. The Solve ME/CFS Initiative (SMCI)'s Carol Head joined the Washington, DC #MillionsMissing before SMCI's Advocacy Day on Capitol Hill. Ron Davis and Janet Dafoe spoke in San Francisco in honor of their son, Whitney.

#MILLIONSMISSING

Toronto represented #MillionsMissing Canada with a demand to Prime Minister Trudeau to listen to ME patients and take action.

#MEAction, through the wonderful work of organizers, is building a strong presence in Canada, and there were several virtual actions with a robust social presence.

#MILLIONSMISSING

#MillionsMissing events took place in **Mexico City, Mexico, Guatemala,** and in **Santiago Chile.**

#MEAction organizers reported that new people engaged in conversation and there was much support from family and friends.

#MILLIONSMISSING

UNITED KINGDOM

The #MillionsMissing held demonstrations, rallies, and visibility actions in 29 locations, from **Birmingham** to **Edinburgh**, **London** to **Southhampton**.

Edinburgh hosted Stuart Murdoch, lead singer of the group Belle and Sebastian, who has ME, and had the 'flash mob' Sing in the City perform. They ended with a "massive lie-down" to represent those incapacitated by ME. Sheffield was bright with art and music, featuring performances from dancers and musicians. St. Helen's showed us what just a few people with an indomitable spirit can accomplish.

In Newry, Northern Ireland, #MEAction and Hope for ME & Fibro joined forces. Unrest was shown at Newry City Hall, and a discussion with a panel of experts was held afterward. And in Southhampton, a massive array of shoes were displayed in a town square "reminiscent of war graves."

#MILLIONSMISSING

Creative displays and music were a huge part of the European #MillionsMissing actions.

Bielefeld, Germany had an illness imitation suit to give people an idea of what it would be like to have ME. Berlin featured dance, and five tele-avatars from No Isolation to bring bedridden pwME to the event. Sweden was filled with song and Norway had partner support from Norway's ME society. A lot of institutions supported the efforts of #MillionsMissing in Prague, Czech Republic. Doctor Olli Poli gave a speech in Helsinki, Finland and, in Amsterdam, #MillionsMissing opened the stock exchange.

In Châteaubourg, France a member of parliament, mayor, and several members of local municipality council joined #MillionsMissing. Switzerland hosted an international visibility action.

#MILLIONSMISSING

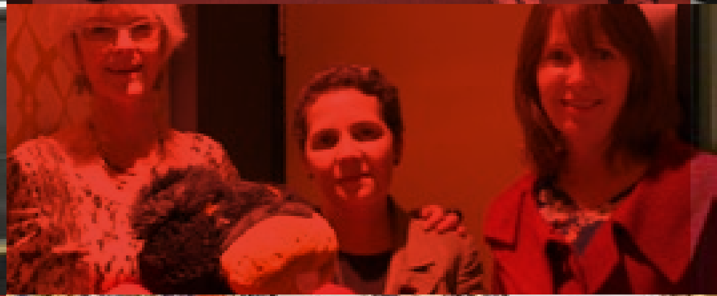
AUSTRAILIA & NEW ZEALAND

Five Australian cities participated in #MillionsMissing citywide events and many more people joined the fight privately and virtually.

Sydney represented with personalized signs and a shoe display. In Caloundra, #MillionsMissing was the "reddest, noisiest cafe table," and brought strangers together to mobilize for the future. Melbourne, Kingston Beach, and Fremantle hosted #MillionsMissing events and asked #CanYouSeeMEnow?

In New Zealand, events both big and small – from Christchurch to Auckland to Taruanga to Hamilton – made an impact.

#MillionsMissing events aligned themselves with the Nurse's Day March, helping to create open dialogue with a vital part of the medical community. Outdoor displays encouraged passersby to learn and interact. There was a screening of Unrest at The Embassy Theater, where shoes were displayed and a small group made a powerful statement by lying down in a public space.



#MILLIONSMISSING

For the first time, #MillionsMissing events took place in Asia, including actions in **Pakistan** and **Japan**.

#MillionsMissing Tokyo's event was attended by clinicians and included a film screening.

#MILLIONSMISSING

More African countries got involved in this year's #MillionsMissing than ever before.

Groups from Zimbabwe, Zambia, Kenya, Botswana and Ghana joined together with South Africa. #MillionsMissing South Africa streamed live on Facebook, featuring meaningful signs and stories from caregivers and allies. The ME/CFS Foundation South Africa organized screenings of Unrest. In Ghana, the Rare Disease Ghana Initiative expressed their solidarity.

#MILLIONSMISSING

Last but not least, **thousands mobilized online**, with patients and families sharing their stories on social media via the #MillionsMissing hashtag.

Many joined a 24-hour, Auckland to Honolulu video chat and virtual rally. See more of the many creative images from the protest by searching for #MillionsMissing on Facebook, Twitter and Instagram.

#MEAction

Statements of Financial Position September 30TH 2017 - September 30TH 2018

	SEPTEMBER 30TH 2018	SEPTEMBER 30TH 2017
ASSETS		
CASH	$110,606.67	$11,602.54
OTHER CURRENT ASSETS	$6,614.42	$6,212.70
TOTAL CURRENT ASSETS	$117,221.09	$17,815.24
LIABILITIES		
ACCOUNTS PAYABLE	$3,548.45	$326.25
OTHER CURRENT LIABILITIES	$1,048.95	$8,736.08
TOTAL LIABILITIES	$4,597.40	$9,062.33
EQUITY		
RETAINED EARNINGS	$481.26	$381.26
FELLOWSHIP	$5,000.00	
NET INCOME	$107,142.43	$8,371.65
TOTAL EQUITY	$112,623.69	$8,752.91
TOTAL EQUITY AND LIABILITIES	$117,221.09	$17,815.24

Statement of Activities

	AS OF SEPTEMBER 30TH 2018
ORDINARY INCOME	
Small Dollar Donations	$261,437.04
Large Dollar Donations	$154,500.00
MERCHANDISE/EVENTS	$9,502.83
INTEREST	$.58
TOTAL INCOME	$425,440.45

EXPENSES	
PROGRAMS	$228,002.32
OPERATIONS/MANAGEMENT/FUNDRAISING	$85,222.23
SUSPENSE	$19.02
TOTAL EXPENSES	$313,243.67

*Other Expense 77000 Exchange Gain or Loss 948.49 Total Other Expense 948.49 Net Other Income (948.49) Net Income 107,142.43

Team

Jennifer Brea *(Co-Founder / Volunteer Executive Director)*
Jennifer Brea is an independent documentary filmmaker based in Los Angeles. She has an AB from Princeton University and was a PhD student at Harvard until sudden illness left her bedridden. In the aftermath, she rediscovered her first love, film. Her Sundance award-winning feature documentary, Unrest, has screened in over 30 countries and had its US national broadcast on PBS's Independent Lens. She is also co-creator of Unrest VR, winner of the Sheffield Doc/Fest Alternate Realities Award. An activist for people with disabilities and chronic illness, she co-founded a global advocacy network, #MEAction and is a TED Talker. @jenbrea

Laurie Jones *(Managing Director)*
Laurie has years of experience working in non-profits and the arts. Prior to joining the #MEAction team, Laurie was the Director of Impact for Unrest, using the film to educate and advocate for those in the ME community. She has served as Programs Director at Brave New Films, worked on the Why Poverty? film campaign and fundraised for United Way of Metropolitan Chicago. She has a BA in Production Studies in Performing Arts from Clemson University and an MA in Applied Human Rights from the University of York. laurie@meaction.net

Ben HsuBorger *(Global Community & Campaigns Director)*
Problem-solver, project manager. Over the past 10 years Ben has worked in nonprofit, academic and government organizations on projects spanning: microfinance, study-abroad, public health, fair housing and community development. He is a former Fulbright scholar eager to help teams innovate through better integration of people, processes and information. He loves extra-large whiteboards. @hsuborger ben@meaction.net

Jaime Seltzer *(Director of Scientific and Medical Outreach)*
Jaime Seltzer was an educator in the sciences when she contracted ME. Through research, determination, and the help of hundreds of other patients posting their experiences, she was able to restore some of her well-being. Seltzer did freelance writing before accepting a position as an Assistant Professor in graduate-level Organic Chemistry. In 2016, she was hired as Managing Editor for #MEAction, where she played a key role in organizing the #MillionsMissing protests, engaged with representatives on Capitol Hill, the CDC, and the NIH, and represented #MEAction at scientific conferences. In 2017, Seltzer was hired to work at the Stanford Genome Technology Center, doing benchwork and research writing, helping to create disease models and investigate treatments. jaime@meaction.net

Adriane Tillman *(Editor & Communications Manager)*
Adriane graduated with degrees in literature and Russian language. She worked as a newspaper journalist for five years, had a few stints in organic farming, and consulted in marketing and copywriting before joining #MEAction. adriane@meaction.net

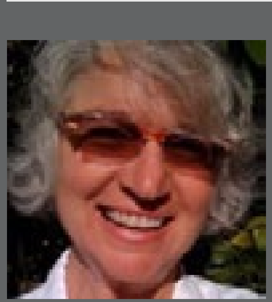
Erin Roediger *(U.S. Advocacy Manager)*
Erin began her professional career working for health non-profits. She has worked as both an events manager and volunteer coordinator with her focus on ensuring individuals felt connected to the cause and were energized to take action. While working, Erin supplemented her knowledge by earning a Masters in Clinical Psychology at Pepperdine University, providing a deeper understanding into human relationships and connections. She has also worked on several electoral campaigns. Training volunteers on these campaigns, Erin witnessed firsthand how a powerful group of individuals can create change in their communities, especially when they are working together towards a common goal. erin@meaction.net

Espe Moreno *(UK Coordinator)*
Based in London, Espe previously worked for the Time for Unrest impact campaign in the UK, overseeing social media, events, and various advocacy efforts. She is a marketing, film and communications professional with 10+ years of international experience in campaign management, film distribution and festivals, startups and nonprofits. Espe has a Masters of Journalism and International Relations from Monash University and a BA in Journalism. espe@meaction.net

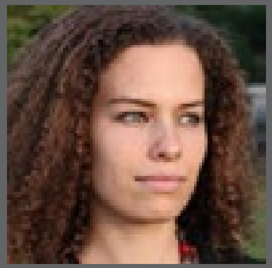
Holly Latham *(Social Media Manager)* Holly has been an enthusiastic volunteer in a variety of capacities in the ME community for years. She had two strong passions prior to illness: facilitating compassionate communities and advocacy. She was on track to turn these passions into a career with a psychology major and goals of a master's degree and doctorate until ME struck and derailed her plans. Holly worsened from more moderately ill to 23.5 hours a day in a darkened room holding on through the pain and hoping for better days. Eventually, those better days did come and Holly immediately turned to the active online ME community. She jumped right into advocacy as a co-manager of the Justice for Karina Hansen campaign. She has since volunteered in a variety of roles through #MEAction where she has used her talents for advocacy and community building. Holly is excited to serve the community in the role of social media manager. holly@meaction.net

Bri Weis *(Office Manager)*
Bri worked in nonprofit management for five years prior to working with #MEAction. She has a Bachelor of Arts degree in Fine Art, and studied accounting in graduate school. She opened and managed a franchise restaurant for three years prior to working with nonprofits. This experience taught her that she could tackle any task set before her, and now nothing is daunting to Bri. She enjoys working with everything from numbers to graphic design. brianne@meaction.net

Board

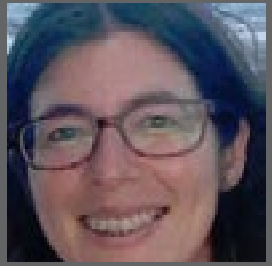


Pam Laird *(Board Co-Chair)*
(im)patient. creative. Prior to onset, she earned her BS in Journalism and MBA from Northwestern University, won a San Francisco Woman Entrepreneur Award. Post onset, she got her MFA in Creative Writing at San Francisco State University. Her thesis, Looking for Pam, observes the process of re-making a meaningful life with a chronic, invisible, misunderstood, and maligned illness. She served on the Solve ME/CFS Initiative Board of Directors in 2013 & 2014.



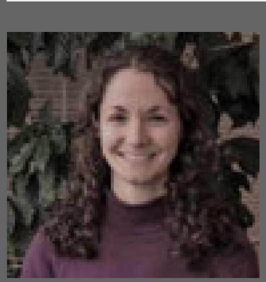
Jennifer Brea *(Board Co-Chair)*
filmmaker, academic and community organizer. She earned her bachelor's in political science from Princeton University and is a Ph.D candidate at Harvard in political science and statistics. In addition, she is directing a Sundance-supported documentary on ME, Unrest. @jenbrea

Ryan Prior *(Secretary)*
is a multimedia journalist and social entrepreneur. He was the founder and editor-in-chief of the Georgia Political Review and went on to write for The Daily Beast and USA Today. Currently working at CNN, he was selected as a Stanford Medicine X ePatient Scholar and was recognized as ProHealth's 2014 ME/CFS Advocate of the Year. He is president of the Blue Ribbon Foundation and serves on the Board of Directors for #ME Action Network. He is a graduate of the University of Georgia. @r_prior

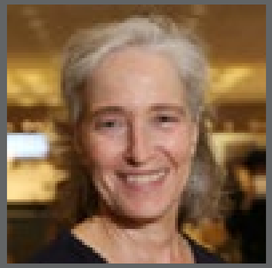


Beth Mazur *(Treasurer)*
Person with ME and science nerd. Beth earned her Bachelor's in Computer Science and Electrical Engineering from MIT. She is interested in how to best use technology to empower ME patients and achieve health equality. She worked as a developer and technical product manager for various for-profit and non-profit technology companies including the Grameen Foundation and Jaspersoft.

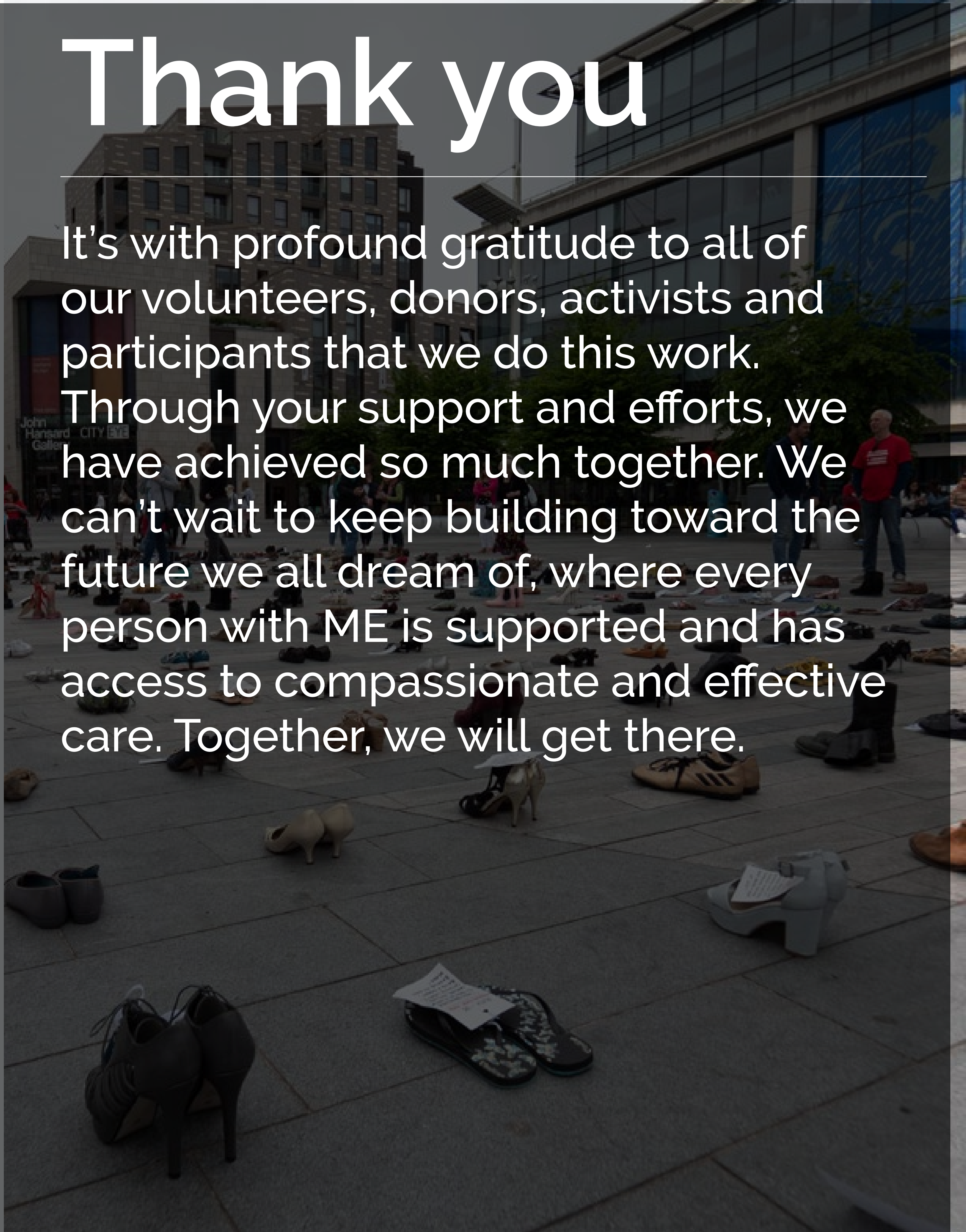
Advisors to the Board



Katie Bach
Katie Bach is the Managing Director of the Good Jobs Institute (GJI), a non-profit that helps companies improve job quality while better enabling employees to provide a great customer experience. Prior to joining GJI, Katie was a Director of Global Strategy at Starbucks, where she led the company's annual strategic planning process. Before Starbucks, Katie spent 5 years in management consulting, first with McKinsey & Company, and then with a start-up firm in Kenya. Katie has an undergraduate degree in Politics, Philosophy, and Economics from the University of Oxford. She was valedictorian of her Master's program at the London School of Economics, and received her MBA from MIT Sloan School of Management. At MIT Sloan, she won a Siebel Scholarship, McKinsey Award, and Forte Fellowship, all for outstanding academic and leadership contributions.



Judy Gayer
Judy is Vice President and Deputy General Counsel – General Corporate at Freddie Mac, where she leads a team that handles commercial transactions, intellectual property, privacy, data security, real estate and other general corporate matters. Judy holds a B.A. in Economics from the University of Michigan and a J.D. degree from the Harvard Law School. She is a past President of Fairfax Court Appointed Special Advocates (Fairfax CASA), a nonprofit that serves the best interests of abused and neglected children in Fairfax County, Virginia. She also provides pro bono legal assistance and otherwise volunteers with various nonprofit organizations in her area.



Thank you

It's with profound gratitude to all of our volunteers, donors, activists and participants that we do this work. Through your support and efforts, we have achieved so much together. We can't wait to keep building toward the future we all dream of, where every person with ME is supported and has access to compassionate and effective care. Together, we will get there.


#MillionsMissing
YOU CAN'T IGNORE → ME ← NOW!!!
#millions missing
Millions Suffering! DECADES GONE!
#millionsmissing
#MILLIONSMISSING