



2017 Annual Report



"When I was first diagnosed with ME in March of 2016, I reached out to #MEAction for support because I couldn't believe what I was witnessing in the world of ME---everything from people with ME being forcefully removed from their homes to daily assaults and micro-aggression in the form of stigma, discrimination and health inequality. I couldn't believe the nightmare I had walked into. As a long time AIDS activist I'm no stranger to fighting however it was now about fighting for my life and the ME community. I will not accept the fact that millions of people with ME around the globe are being treated this way and am thankful to #MEAction for supporting and empowering me to speak truth to power until this nightmare is over."

- Terri L. Wilder, Person with ME



Our Vision

A world that
understands, supports,
and cures all people
with ME.

Our Mission

Grow and mobilize a
community of patients
and allies to be strong
and effective advocates
for people with ME and
related conditions.



WHO WE ARE

#MEAction is 501(c)3 non-profit organization and international network of patients fighting for health equality for Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome. We support patients, build community, and empower people with ME and their allies with the technological tools and advocacy training needed to mobilize and grow our movement for change.

We were founded with the belief that while we may find it difficult to advocate for ourselves in the physical world, in the virtual world, we can be an unstoppable force.

WHAT WE DO

We focus our efforts in three main areas:

- 1)** Connecting and supporting people with ME, their loved ones and allies,
- 2)** Educating people affected by ME and the general public
- 3)** Organizing people with ME and their allies to take action for long-term research, policy, and cultural change.

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Connect and Support

It is a challenge to unite as a community when this disease confines so many of us to our homes or beds, leaving us isolated, with few people who understand what we are going through. #MEAAction develops tools and organizing strategies to empower people with ME to break out of the physical isolation and confront the stigma. Through storytelling, virtual support groups, and the camaraderie forged from working together – on everything from research surveys, to congressional and parliament outreach, to #BedFest, a virtual art & music festival – we are connecting a vibrant community to build a better future.

Supporting Patients

In 2017, we realized that we needed to be more than a hub for activists. We needed to build resources to support patients, whether they were newly diagnosed, in crisis, or otherwise seeking help.

So we launched “Living with ME,” a support group that lives in multiple formats – a Facebook group, a weekly telephone support group and a monthly video chat.

We also launched a global directory that allows patients to find doctors, support groups and other resources in their area.

#MEACTION GLOBAL DIRECTORY



Find a doctor or a support group near you, browse research organizations, and find out ways to get involved in your community! Use [this form](#) to suggest an addition or correction. [Click here](#) to view ME/CFS specialists in document form.

Type	+	Primary specialty	+	Country	+	:
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"Think of it as a sort of "second life," bringing together people from a wide range of professions and passions, and empowering them to create and contribute again. Artists with ME make art. Scientists with ME discuss and collaborate on research. Veteran ME parents give advice to expectant mothers. Former lawyers and policymakers strategize on political outreach. Together, we are building something big and bold to change the world."

- Jennifer Brea, co-founder, #MEAAction



Growing Community

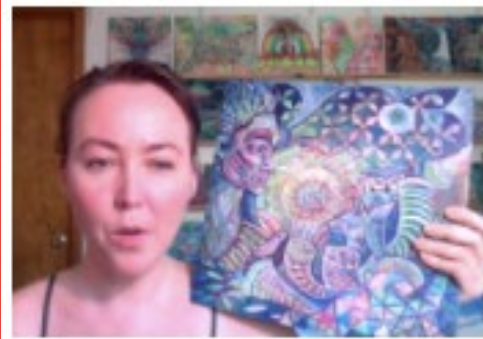
We continued to grow our online communities, involving more people with ME and allies than ever before. Our main Facebook page is followed by over **10,000** people and our email list reaches over **20,000 subscribers** around the world. We have **a global volunteer network of over 200 people** working together on projects to fight for ME equality. We've launched dedicated Facebook groups including #MEAAction USA, #MEAAction Global, #BedFest, and #MillionsMissing, ranging in membership from 300-700 per group. Through these online hubs of interaction, we are able to connect people with ME to those with similar goals, projects, and dreams of a better future, creating a foundation of support and connection to catalyze and grow our movement.



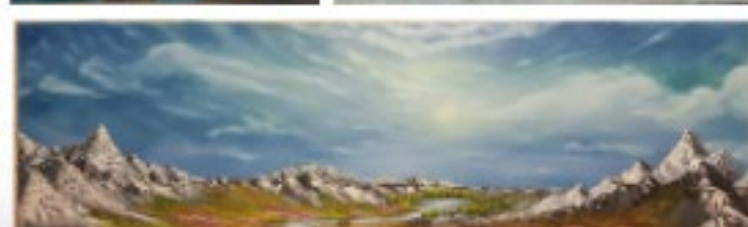
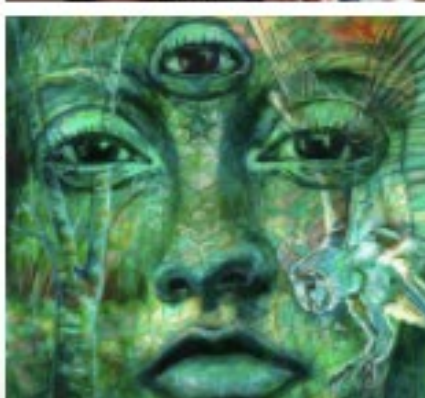
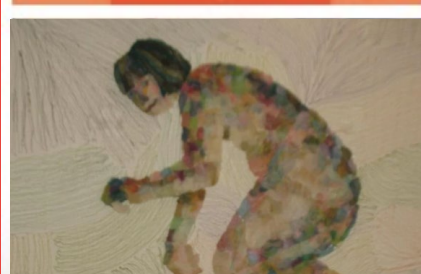
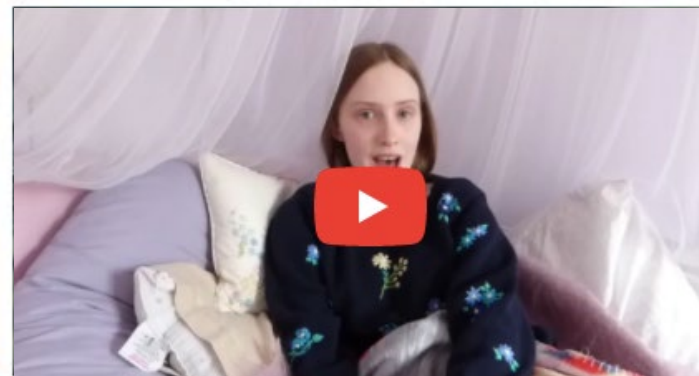
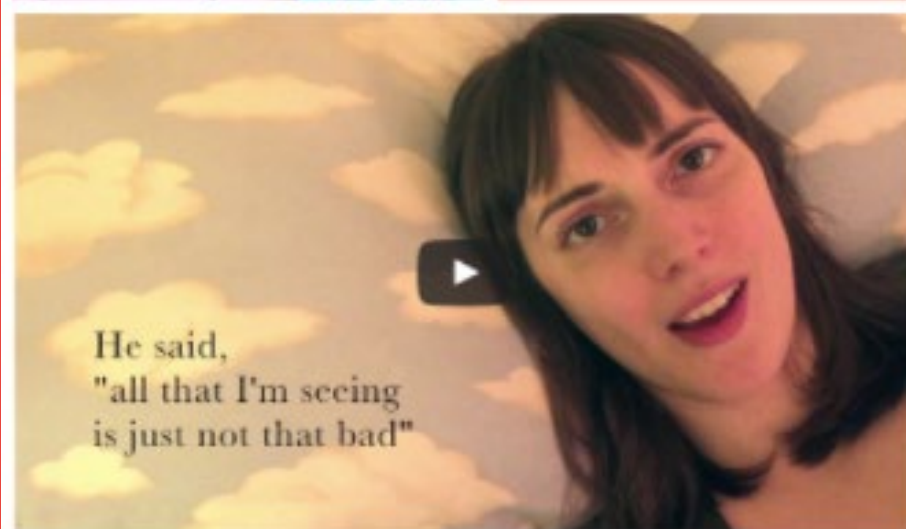
#BEDFEST

Click on the images below to listen to music and learn more about the stories behind the art. For more, visit <http://bedfest.meaction.net>.

Share



Welcome to
#BedFest 2017!
presented by
#MEAction



Virtual art & music festival

Bedfest was a virtual art and music festival that brought together dozens from around the world to share their art and craft. It was an opportunity to raise awareness and express what it is to live with ME, as well as an opportunity to network artists with each other. From the Civil Rights Movement to the movement for people with HIV/AIDS, art has always played a crucial role in empowering communities, confronting injustice and helping the broader public see and understand experiences outside their own.



"#BedFest was quite the occasion. People appeared in PJ's, crumpled t-shirts, crochet vests, keen to address the wider world, share art & music, raise ME-Awareness. We didn't have to leave the house! Teachers, engineers, pilots, students, social workers, and an opera singer; kids, teens, adults of all ages and from three continents; mothers, fathers, lovers, friends; people who – before the fall – led active lives. So much loss, so much determination, and a strong sense that we're not desperate because we're ill (hard as it is), but because we have been disregarded, even disparaged for years."

- Marion Michelle, Person with ME



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Advocate

We live in a world where you don't get the basic resources you need unless you build the power to demand them. This is especially true for those of us with invisible and stigmatized disabilities. #MEAAction used this year to focus on US-based advocacy work at the local, state, and national levels and support UK parliament outreach. Check out some of our accomplishments!

Congressional Briefing & Lobby Week (US)

#MEAAction, in partnership with Solve ME/CFS Initiative (SMCI), organized a congressional briefing on Capitol Hill to educate legislators on the urgent need to fund ME/CFS research. The briefing was introduced with a moving speech from **Senator Ed Markey** (MA) followed by presentations from #MEAAction co-founder Jen Brea, SMCI Chief Scientific Officer Dr. Zaher Nahle, and President of SMCI, Carol Head. The briefing was well attended by legislative staff, who now have this issue on their radar.

The same week, thanks to hundreds of volunteers and our amazing partner, SMCI, we had over **70 meetings** with House and Senate offices in D.C, including 8 meetings with Congress members, in addition to dozens of local district office meetings the week before. For those who couldn't join us at district or DC meetings, we had an online action resulting in over **3,327 messages** to Congress about ME!

These kinds of actions are not easy for anyone in our community, but we stepped (and rolled!) up, joined forces, and made a significant impact on moving forward Congress' education on ME issues. The spirit and determination from all participants was amazing to witness.





"For the whole time I have been sick, 27 years, we never had an organization that could foster and build an advocacy community for ME patients. And now, in just a few short years, MEAction has become that indispensable organizing platform and clearing-house for patients struggling to get health equality and funding parity. MEAction has become crucial to us getting back our lives."

- Rivka Soloman, Person with ME





Parliament outreach (UK)

#MEAction UK mobilized around **Early Day Motion 271**, a motion in support of reviewing the NICE guidelines. Patients and allies urged their MPs to sign the motion, resulting in signatures from 77 members of parliament.

The **#TimeforUnrest** campaign partnered with the ME Association and the Countess of Mar to screen an excerpt of *Unrest* to 40 Members of Parliament. After the screening, #MEAction mobilized thousands of patients and allies to reach out to their Members of Parliament asking them to watch the film by requesting a screener. To date, over 70 additional members have requested to watch *Unrest*.

Our asks? The reform of medical guidelines, the establishment of centers of excellence (specialty clinics for both care and applied research), and investment in research funding.



Represent

#MEAction was accepted to serve on the board of the national Chronic Fatigue Syndrome Advisory Committee (CFSAC) and will use this role to continue to advocate to end the health inequality for ME community members at the federal level. We will be participating in bi-annual meetings that help steer the direction of federal approaches to the treatment of ME.

Website Hub

A global hub of activism, our website enables activists to submit their own petitions, actions and articles, and provides resources and toolkits to support strategic advocacy. We also continue to provide in-depth reporting on the latest scientific research and policy news.

Promoting Patient Engagement

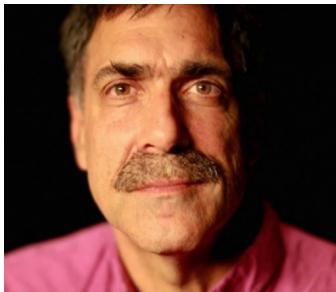
We drafted a document on “Engaging People with ME as Partners in the Collaborative Research Centers” in order to help US researchers think practically about how to engage patients as partners.

New York Advocacy campaign

#MEAAction supported advocacy efforts leading to multiple milestones in New York, including a State Resolution sponsored by Senator Brad Hoylman and a letter about ME from the office of the State Health Commissioner which was sent to **85,000 medical providers!** The Health Commissioner letter was also posted on the New York State health provider portal - and people from around the world have contacted their office to use this letter as a model for their work.

State Resolutions

#MEAAction proudly supported activists to achieve additional state resolutions in California, Georgia, and Illinois, in addition to a proclamation by the Governor of Massachusetts. We will continue to support these advocacy and awareness efforts by our community members across the globe.



"When I needed help figuring out how to set up a crowdfunding campaign, ME Action provided terrific technical support and advice. And once the campaign was launched, the ME Action network provided an amazing level of support."

- **David Tuller, DrPh,** Academic coordinator of University of California, Berkeley's
Joint Masters Program in Public Health and Journalism



#MEAction has facilitated coordinated action at an international scale that we have never seen in ME activism before. Of equal importance is the way #MEAction has encouraged and supported projects of individual initiative. Combined, these two approaches have brought many new advocates into the movement.

- Jennie Spotila, Person with ME





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Organize

Our education and advocacy work is only as good as the man and woman power behind it. To build that power to the scale needed for real change in our lifetimes, we have to be continuously stay visible and add new people to our efforts. And we must have strategic follow-through on our demands. Here are some of the actions we took this year.

Millions Missing Protests

#MEAAction supported the development of key demands through a deliberative community process, leading to demonstrations in eleven cities in May 2016, twenty-five cities in September 2016, and eighteen cities in May 2017. That's a total of **54 mobilizations** on **three continents**, in addition to massive online participation. Over **60 news outlets** covered these protests!







Outcomes

These protests led to a number of successful outcomes. In the **United States**, it led to two meetings with the Assistant Secretary of Health which led to increased patient representation on CFSAC. In **Canada**, the government reached out to the National ME/FM Action Network to discuss steps forward for ME. In the **Netherlands**, a member of parliament sent a letter to the Minister of Health to follow-up on the ME protest demands, while in **Norway**, activists met with a politician in Parliament to discuss their demands. Additionally, in **South Africa**, a program on ME/CFS aired on national television.

Time for Unrest Campaign

#MEAction is the main organizational partner of the award-winning documentary film, *Unrest* and its global social impact campaign, "Time for Unrest." #MEAction is working with the campaign to use screenings and actions around *Unrest* to strengthen the growing movement advocating for more recognition, education, research, and funding around ME. [Click here](#) to learn more about the campaign.



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WHERE WE ARE GOING

We have been able to accomplish so much in 2017 - and we are thrilled to expand and prepare for an even more influential 2018!

Some exciting plans for 2018 include:

Patient Support Resources

#MEAAction knows that it is still far too difficult for patients, caregivers, and medical providers to find clear, concise information about ME - from initial diagnosis to ongoing treatments to how to deal with the disease at work, with family, and beyond. That's why we are committed to making sure that all of these communities are able to come to one place to get all of the best resources that exist to help navigate this complicated journey - and that they can use these resources to pass on to others and continue the ripple effect of education.

Getting Local, Going Deep

In addition to our national-level work and supporting others' state-level advocacy work, we will dive deeper into several local communities to intensify our work in targeted cities and states to help support organizing hubs with specific short-term and long-term goals. Through this groundwork, we will be able to make critical inroads at the local level, build models for other states to employ, and build local activist hubs ready to play larger roles in national and global actions.

Building Leadership

Movements falter under narrow leadership and thrive when all of us are empowered to lead in whatever ways we can. #MEAAction is committed to strengthening this movement through intentional development of strong leaders capable of expanding our activism both deep and wide. Through educational training videos, advocacy teach-ins and toolkits, and hands-on community mobilizations, we will support existing leaders and identify and develop new leaders in all areas of our work.

Millions Missing

In 2018, we look forward to our largest #MillionsMissing mobilization yet, building on the expanded awareness, opportunities, and allies from our first three global mobilizations and the #TimeForUnrest campaign.





Thank you for all of your support that enables us to do this powerful work. We are looking forward to another impactful year together.

Onward!

**Jennifer Brea
& the #MEAAction Team**

