

# #MEACTION USA STATE CHAPTERS



## PURPOSE

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Since our inception, #MEAction's vision has been to create a world where all people with myalgic encephalomyelitis (ME) have support and access to compassionate and effective care. Our mission is 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 community is the backbone of this organization and the power behind so much of our impact. Local #MEAction activists have organized #MillionsMissing in hundreds of cities across the globe, passed resolutions and motions in Congress, Parliament, state legislatures, and made major strides in medical education.

#MEAction USA aims to grow our community's impact through the expansion of our formal state chapters. State chapters build local volunteer capacity around volunteer engagement, congressional outreach, local and state advocacy, medical education, and support awareness raising efforts for ME. State chapters will also act as laboratories to incubate new ideas for advocacy and outreach: successes in one state can be shared and propagated across the country. We want to build a strong, national, distributed network of patient activists and allies to grow the movement for health equality.

# GOAL

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In the coming months, we'll be organizing planning calls with our nine, established state chapters and offering a rolling application process to bring new states online. As we grow as an organization, our goal is to expand our State Chapters to new states and launch City Chapters in major cities across the nation.

## Our State Chapters will:

- Engage local and state public health departments and elected officials to raise awareness and demand change for ME
- Advocate for the passage of local proclamations, state resolutions, and legislation
- Engage local hospitals, universities and clinics to educate health care providers and improve access and quality of care for people with ME
- Organize Unrest continuing medical education screenings
- Deepen volunteer engagement and grow local activists' organizing and advocacy skills
- Build strong, local networks of support and friendship



## WHY STATE CHAPTERS MATTER

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We have to build this movement from the ground up. Only by acting locally can we transform our communities and grow our capacity to make an impact on a national stage. That's why changing the world for people with ME starts with you.

## Benefits of State Chapters:

- Coordination and learning between states
- Access to our State Chapters' Handbook
- Personalized email accounts
- State websites
- Digital Advocacy Tools (petitions & contact state legislators)
- Fiscal sponsorship
- Access to Bluejeans for hosting of State Chapter meetings
- Training webinars and other tools
- Strategy support from MEAction HQ
- ...and more!

# STATE CHAPTER STRUCTURE

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Within each state chapter, our vision is to have designated volunteers fill assigned roles, as we will call them moving forward, "Chairs," and perform the tasks necessary within each role, with support from sub-committees, depending on the size of each chapter. What works best will depend on the capacity and goals within the state– we will work with you to figure out what works best for your chapter!

The structure of #MEAction USA's State Chapters, focuses on action in three major areas (as able, depending on the size and scope of your group): advocacy, education and events, and #MillionsMissing. With this in mind, we have defined chair roles to bring these major areas into focus:

## **STATE CHAIR**

### **ADVOCACY CHAIR**

### **EDUCATION & EVENTS CHAIR**

### **#MILLIONSMISSING CHAIR**

We understand that volunteering as a person with ME can mean at times you do not have the energy or the time to serve in the full capacity of the position. This is why we encourage co-chairs (or even tri-chairs!) We would never encourage you to push yourself past your energy envelope.

**Here is a brief overview of the role of each chair:**

### **STATE CHAIR:**

The State Chair recruits and leads the volunteer state leadership team (Advocacy, Education & Event, #MillionsMissing). Working alongside their staff partner, the State Chair guides and encourages their volunteer state leaders to implement national priorities on a local level and pursue strategies that will have the most impact in their state. Also, they focus on ensuring the state leadership team is productive and has the resources needed for success.

### **ADVOCACY CHAIR:**

The Advocacy Chair leads the advocacy program within their state. This position will focus on accomplishing national and state advocacy priorities including legislation and policy change, while building the volunteer base who can take advocacy actions across the state.

### **EDUCATION & EVENTS CHAIR:**

The Education and Events Chair helps to educate the local community and grow awareness of ME among the general public as well as medical professionals. They will engage local press, organize Unrest continuing medical education events and support other awareness-raising projects. They may also organize support calls and social events for people with ME and their families.

### **MILLIONS MISSING CHAIR:**

The #MillionsMissing Chair plans the local #MillionsMissing protest on the internationally scheduled day. Working alongside their staff partner, they will plan an event to share the stories of people with ME, engage the community in taking action, and accomplish the goals set by #MEAction USA.

## MORE ABOUT THE STATE CHAPTERS' HANDBOOK:

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One of the most important aspects of being a designated State Chapter is access to our State Handbook, a collection of learnings, toolkits and step-by-step guides on how #MEAction activists and volunteers can advance our work on the state level. Plus, even some new exciting opportunities that will be coming soon! Here is what will be featured in the Handbook:

- *State resolutions*
- *City proclamations*
- *Creating a petition*
- *How to host an Unrest Continuing Medical Education (CME) screening*
- *#MillionsMissing*
- *State Legislation*
- *State Department of Health Outreach*
- *Postcards to Doctors*

Over time, we will continue to add to the list as our amazing community continues to innovate new ways to engage on a state level.

Here are just some of the successes our State Chapters have had over the last year:

### NEW YORK

#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](#)."

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 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.

### FLORIDA:

#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.

## **TEXAS:**

#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.

## **GEORGIA:**

In 2018, #MEAction Georgia began hosting two meetings (virtual) per month, one devoted to advocacy, the other devoted entirely to support.

#MEAction Georgia 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.

## **CALIFORNIA:**

In June 2019, members of #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.

Thank you!

We are so grateful for the work of the #MEAction USA State Chapters! If you are interested in becoming a #MEAction USA State Chapter Leader or want to get involved with an existing chapter, email [erin@meaction.net](mailto:erin@meaction.net).

You can also connect with other organizers in your state via our [State Facebook Groups](#).