



#MillionsMissing 2019

May 5th to 12th, 2019

#MillionsMissing is a global campaign for health equality for people with Myalgic Encephalomyelitis (ME), organized by the non-profit #MEAction. Take action with us by hosting a large demonstration or small gathering in your community. Or, protest from your bed via social media!

Our story is urgent: for decades people with ME have been grossly neglected by our governments. The numbers are damning: biomedical research for ME continues to be severely underfunded according to the disease burden of ME (the number of people affected and the severity of the disease).

We've made important strides in making our voices heard before our government leaders across the world, but we have much more to do. More than ever, we need to grow our movement and remain persistent in our demands for urgent, sweeping change, for equitable research funding and care, accurate medical education and an end to the harm and stigma.

Last year was our largest global protest ever with 100 cities around the world demonstrating, and even more participating virtually. Our story was told 79 times by the press around the world. And this year will be even larger.

Now is the time to take our fighting spirit and creativity to the streets once more. We must send a message to our government representatives that we are here, we are fighting for our lives, and we are not going away.

[Read more](#) and visit millionsmissing.net.

The Plan

Demonstrations will take place around the globe throughout the week of May 5th-12th, 2019. Join the movement!

Each demonstration should decide what targets (it can be general or specific) will be most impactful for drawing attention at your location. We aren't dictating specific targets this year by country as we did in previous years.

The main goals are:

To Be Seen: Inspired from many of last year's protests, we aim to be creative and be seen by making a visual impact!

To Take Concrete Action: Pick a target and demand fair treatment and equitable research funding.

Get Started

Choose the level of event that makes the most sense to you from the options below. If you are someone with ME, we suggest focusing on a smaller event or partnering with allies on a larger event.

Ultimately you know your body best and how you participate in #MillionsMissing is up to you. We know this fight will be long and hard, so sustainability is key! Pick one of the levels that works best for you.

Pick a category from these options:

Option 1) [Individual / Virtual](#)

Option 2) [Intimate](#) (a few friends / family)

Option 3) [Neighborhood / Community](#)

Option 4) [City-wide](#)

[Appendix of Resources](#)

[Individual/Virtual](#)

In today's world of social media, a protest doesn't have to happen in one place at one point in time for the world to take notice. We are linking ourselves through our hashtags of #MillionsMissing with the goal of demanding justice from our governments.

Examples of #MillionsMissing social media posts from last year:



Date

May 5th - 12th - with the focus on May 12th

Event Location

- Online / Your home

BEFORE May 5th- May 12th

[CLICK HERE](#) for full details on how to prepare to protest virtually leading up to the #MillionsMissing.

ON May 5th - 12th:

[CLICK HERE](#) for full details on how to protest virtually during the #MillionsMissing.

Find Support

Join the conversation on our #MillionsMissing Facebook [group](#).

Email millionsmissing@meaction.net with questions.

Intimate (a few friends and family)



BEFORE Your Event:

1. Choose an event date - May 5th to May 12th
2. Choose an event location
 - Your home
 - A friend / family member's home
 - A public space like a park or town courtyard
3. [Register your event](#). You only need to fill out the first page, but you must scroll down on the second page and press the submit button in order to register.

Even if you are a few people with plans to take action from your home, we want to show who is participating and where so that we can point to the widespread nature of this disease and say to our governments, "Look, we had people from every one of these towns show up."

If you want to lead or help organize a demonstration or event, get in touch with ME activists in your hometown to start communicating about the plan. Find a local #MEAction Facebook group near you, [here](#).

3. Find a Co-Host(s):

- Friends / family
- Local / state / regional #MEAction advocates
- ME or ally organizations
- Local ally organizations (example: Disability groups, Women's Rights orgs, etc.)
- Colleagues
- I'm doing this by myself (this is totally okay!)

4. Get the Word Out



- [Posters](#)
- Handouts: [US version](#) | [EU version](#)
- T-shirt - [purchase](#) #MillionsMissing t-shirts to show solidarity through branding

6. Spread the word

- Let others know about #MillionsMissing using sample posts

7. Find Support

If this is your first time or you want to go bigger this year, please get in touch with the community to share ideas and for logistical advice.

Join the conversation on our #MillionsMissing Facebook [group](#). We will also be hosting calls led by leaders of past demonstrations. Stay tuned! Email millionsmissing@meaction.net with questions.

DURING your Event:

Program Options:

- Photo Taking ** we are asking everyone to do this! - - [Check out our Photo & Video tips](#) (including instructions on how to do Facebook Live).
- Speakers
- Shoes
- Story Sharing
- Fundraising
- *Unrest* screening

AFTER your event:

Follow up:

- **Share your photos on social media!!!**** This is what will share our success, so we ask you to take a photo, video anything that helps us share! **Include these hashtags:** #MillionsMissing / #CanYouSeeMENow?

Neighborhood / Community

BEFORE your event:

1. Choose an event date - May 5th to May 12th
2. Register your event [here](#).
3. Learn from previous protests - [check out videos](#) and [photos](#) from San Francisco / London / Syden / Denmark etc.
4. Choose an event location:
 - Your home
 - A friend / family member's home
 - Local park
 - Town square
 - Campus
 - Place of worship
 - Library
 - Town hall, city hall or a government building*
 - Hospital or medical center *
 - **This may require a permit*
 - *Note: Picking a place that is visually appealing helps to create a great photo opportunity! Take a group photo holding up your signs. [Check out this image gallery from last year's #MillionsMissing](#) for inspiration. Remember, not all events need to be big - a photo of you at home is enough!*

4. Find a Co-Host(s):

If you want to lead or help organize a demonstration or event, get in touch with ME activists in

your hometown to start communicating about the plan. Find a local #MEAction Facebook group near you, [here](#).

- Friends / Family
- Local / State / Regional #MEAction advocates
- ME or ally organizations
- Local Ally organizations (example: Disability groups, Women's Rights orgs, civic organizations, religious organizations, etc.)
- Colleagues
- I'm doing this by myself (this is totally okay!)

Get Support

If this is your first time or you want to go bigger this year, please get in touch with the community to share ideas and for logistical advice.

Join the conversation on our #MillionsMissing Facebook [group](#). We will also be hosting calls led by leaders of past demonstrations. Stay tuned! Email millionsmissing@meaction.net with questions.

5. Find Allies

#MillionsMissing is a key opportunity to build partnerships with allies in our communities. Think of the groups in your hometown who may be willing to show up to support our fight.

It may be disability rights groups, religious groups, women's rights groups, philanthropic groups or other organizations fighting for justice, health equality and basic human rights.

Also, think about how you can incorporate your family and friends into helping with the logistics of organizing the demonstration. Now, is the time to make that invitation to the people in our lives to join the fight.



6. Get the word out:

- Set up a Facebook Event
- Post about your event on social media - share sample posts from our [social media toolkit](#), or create your own posts.
- [Send invitations](#) to invite others to participate in your Visibility Action
- Reach out local press using our sample press release: [US local](#) (to share with local newspapers and online platforms): [Global version](#)
- Advertise at your doctor's office or local coffee shop - EDIT and [distribute this flyer](#) (copy and paste into a google document in order to edit). *Don't waste too much energy doing this unless you happen to be at the doctor's office or coffee shop or have some eager volunteers. It's fairly unlikely that someone is going to see the flyer and show up so best to put your effort into reaching out to local press or building alliances with community organizations who will show up to support you.*
- Start a personal fundraiser on #MEAction. Soon we will be launching our peer-to-peer fundraisers and we will give you step-by-step instructions on starting a fundraiser to keep our work going. Your fundraiser will support #MEAction's ongoing work in ME education, legislation, research and community building. Find more information about fundraising on page two of the [registration form](#).

7. Think about your Visual Effect:

“Politics is theater. It doesn't matter if you win. You make a statement. You say, "I'm here, pay attention to me.” – Harvey Milk

Protests are opportunities to grab attention, to crystallize all of the emotion (anger, rage, grief, loss, hope, love) of our everyday into a single image. To tell the story of a people demanding justice against a system that -- whether through malice or indifference -- has let generations of people with ME to suffer, languish and die.

How can we encapsulate such a strong, expansive, powerful message in such a way that those who see it can never forget it? How can we ensure that people are talking about it tomorrow at work, finding themselves recalling it hours and days later? How can it make a home in people's hearts?

[Read more](#) for how to give your protest power, visually and emotionally.

- [Posters](#)
- Handouts: [US version](#) | [EU version](#)
- Microphone
- T-shirt - encourage attendees to [purchase](#) and wear a #MillionsMissing t-shirt to show solidarity through branding. Consider purchasing 5 or more (depending on the number of rsvps) to have on-hand to sell to people who didn't get around to purchasing their own.
- **Shoes** - Shoes have been a powerful, uniting vision for #MillionsMissing. Demonstrations across the world have displayed the shoes of people with myalgic encephalomyelitis as representation of what they are missing from their lives.



Here are a few tips for including shoes in your demonstration:

Have a plan for the shoes. If you are planning to display shoes at your event, there are various ways to organize the collection.

- a) You can ask people to bring a few pairs of shoes to represent people with ME, and then encourage them to take them home at the end of the event.

- b) You can ask people to send you shoes. Be clear about what you will do with the shoes afterwards. We recommend donating the shoes afterwards. You can donate them to a local charity.

Include a tag with the shoes that says a little bit about the person - their age, name (or just first name), and how the shoe represents what they are missing from their lives due to ME. Print this [tag](#) to attach to the shoe.

8. Think about your **publicity strategy**:

- Post on Social Media - share sample posts from our [social media toolkit](#), or create your own posts.
- Reach out to local press using our sample press release (still to come).
- Learn about how to talk to the press. Check out our [training guide](#).
- Advertise at your doctor's office or local coffee shop. Here's an example: [distribute this flyer](#) (copy and paste into a google document in order to edit). *Don't waste too much energy doing this unless you happen to be at the doctor's office or coffee shop. It's fairly unlikely that someone is going to see the flyer and show up.*

9. How will you **document your event**:

- **Photo Taking ** this you need to do!** - [Check out our Photo & Video tips](#) (including instructions on how to do Facebook Live).
- Hire a professional photographer and videographer, if possible.

DURING your event:

Program Options (Choose 1-8)

- Speakers
- Partners
- Shoes
- Musical Events/ Poetry/Art - check out these [visual ideas](#).
- Story Sharing
- Non-violent actions/civil disobedience - [watch this webinar!](#)
 - If you choose to do civil disobedience, it is completely up to the organizers and the participants to organize that. Do your research and stay safe.

Examples of creative demonstrations:



AFTER your event:

- **Share your photos on social media!!!**** This is what will share our success, so we ask you to take a photo, video anything that helps us share! **Include these hashtags:** #MillionsMissing / #CanYouSeeMENow?

City-Wide

BEFORE your event:

1. Choose an event date - May 5th to May 12th

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4. Choose an event location
 - Local park
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 - **This may require a permit*
 - *Note: Picking a place that is visually appealing helps to create a great photo opportunity! Take a group photo holding up your signs. [Check out this image gallery from last year's #MillionsMissing](#) for inspiration.*

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- Friends / Family
- Local / State / Regional #MEAction advocates
- ME or ally organizations
- Local Ally organizations (example: local Lyme disease, Fibromyalgia groups, Disability groups, Women's Rights orgs, etc.)
- Colleagues
- I'm doing this by myself (this is totally okay!)

Get Support

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Join the conversation on our #MillionsMissing Facebook [group](#). We will also be hosting calls led by leaders of past demonstrations. Stay tuned! Email millionsmissing@meaction.net with questions.

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Also, think about how you can incorporate your family and friends into helping with the logistics of organizing the demonstration. Now, is the time to make that invitation to the people in our lives to join the fight.



7. Get the word out:

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- Post about your event on social media - share sample posts from our [social media toolkit](#), or create your own posts.
- [Send invitations](#) to invite others to participate in your Visibility Action
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- Start a personal fundraiser on #MEAction. Soon we will be launching our peer-to-peer fundraisers and we will give you step-by-step instructions on starting a fundraiser to keep our work going. Your fundraiser will support #MEAction's ongoing work in ME education,

legislation, research and community building. Find more information about fundraising on page two of the [registration form](#).

8. Think about your **Visual Strategy**:

Make a Visual Impact!

“Politics is theater. It doesn't matter if you win. You make a statement. You say, "I'm here, pay attention to me.” – Harvey Milk

Protests are opportunities to grab attention, to crystallize all of the emotion (anger, rage, grief, loss, hope, love) of our everyday into a single image. To tell the story of a people demanding justice against a system that -- whether through malice or indifference -- has let generations of people with ME to suffer, languish and die.

How can we encapsulate such a strong, expansive, powerful message in such a way that those who see it can never forget it? How can we ensure that people are talking about it tomorrow at work, finding themselves recalling it hours and days later? How can it make a home in people's hearts?

A key goal for 2019 is to use creative visuals to draw attention to our movement.

We encourage each demonstration to undertake creative visual endeavors as we have seen in past years. This is not only important for attracting attention on the day, but also to use as compelling images for our advocacy work throughout the year.

[Read more](#) for how to give your protest power, visually and emotionally.

Last year, Scotland staged a lie-down, Berlin unraveled a banner for ME at a football game, New York made themselves invisible with blue gauze, and Sheffield showed up in red wings.



Shoes:

Displaying empty shoes has always been a unifying and dramatic image to represent the millions missing from our lives due to the neglect of this disease. We encourage you to incorporate this visual into your event or social media demonstration this year, in addition to using other dramatic visuals.

Here are a few tips for including shoes in your demonstration:

Have a plan for the shoes. If you are planning to display shoes at your event, there are various ways to organize the collection.

- a) You can ask people to bring a few pairs of shoes to represent people with ME, and then encourage them to take them home at the end of the event.
- b) You can ask people to send you shoes. Be clear about what you will do with the shoes afterwards. We recommend donating the shoes afterwards. You can donate them to [Soles4souls](#), or any local charity.

Include a tag with the shoes that says a little bit about the person - their age, name (or just first name), and how the shoe represents what they are missing from their lives due to ME. Print this [tag](#) to attach to the shoe.



9. Hire a professional photographer or professional enlist volunteer

Since the movement lives on through social media and in communications with our representatives and government officials, remember that high-quality photography and videography is key!

We encourage you to hire a professional photographer or videographer, or to find a professional who can volunteer their time.

10. Other Props

Items you may need for your demonstration:

- [Posters](#)
- Handouts: [US version](#) | [EU version](#)
- Microphone
- T-shirt - encourage attendees to [purchase](#) and wear a #MillionsMissing t-shirt to show solidarity through branding. Consider purchasing 5 or more (depending on the number of rsvps) to have on-hand to sell to people who didn't get around to purchasing their own.

11. Think about your Publicity Strategy:

- Post on Social Media - share sample posts from our [social media toolkit](#), or create your own posts.
- Reach out local press using our sample press release: [US local](#) (to share with local newspapers and online platforms): [Global version](#)
- Learn about how to talk to the press. Check out our [training guide](#).
- Advertise at your doctor's office or local coffee shop - [distribute this flyer](#) (copy and paste into a google document in order to edit). *Don't waste too much energy doing this unless you happen to be at the doctor's office or coffee shop or have some eager volunteers. It's fairly unlikely that someone is going to see the flyer and show up so best to put your effort into reaching out to local press or building alliances with community organizations who will show up to support you.*

12. Figure out the Program. Options include (Choose 1-8)

- **Photo Taking ** this you need to do!** - - [Check out our Photo & Video tips](#) (including instructions on how to do Facebook Live).
- Speakers
- Partners
- Shoes
- Musical Events/ Poetry/Art - check out these [visual ideas](#).
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- Non-violent actions/civil disobedience - [watch this webinar!](#)
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AFTER your event:

- **Share your photos on social media!!!**** This is what will share our success, so we ask you to take a photo, video anything that helps us share! **Include these hashtags:** #MillionsMissing / #CanYouSeeMENow?

Resources:

Strategy:

- [Visual ideas](#) - how to make your protest visually dramatic

Protest materials:

- [Posters](#)
- [Tag](#) to attach to shoes
- [Merchandise](#)
- Handouts - fact sheet to distribute at protest: [US version](#) | [EU version](#)
- [Photo & Video tips](#) (including instructions on how to do Facebook Live)

Press / advertise:

- [Media Training Manual](#) (if you want to go above and beyond!)
- Sample press releases: [US local](#) (to share with local newspapers and online platforms):
[Global version](#)
- Share sample posts from our [social media toolkit](#), or create your own posts.

Support:

- #MillionsMissing Facebook [group](#)
- Email millionsmissing@meaction.net

