



#MillionsMissing 2018

Saturday, May 12th, 2018

#MillionsMissing is a global campaign for health equality for Myalgic Encephalomyelitis (ME), organized by the non-profit #MEAction. Take action with us by hosting a Visibility Action in your community!

The Plan

In the US, we aim to have at least **one visibility action in all 50** states and target **National Institutes of Health (NIH)** and individual members of **Congress**. Visibility actions will take place **around the globe** targeting decision-makers in those countries.

In the United States, #MEAction will work with visibility action participants to **compile images** of each and every action and in the US deliver to the head of the NIH, Francis Collins, along with the [NIH petition](#) and [global petition](#) we have been collecting.

The three goals of the actions are:

- 1) **To Be Seen:** We must have the world see those with ME in order to build a movement that fights for change.
- 2) **To Take Concrete Action:** We will gather photos & petitions to show our leaders who we are and demand more funding for research

- 3) **To Demand a Meeting with Francis Collins:** Francis Collins must meet with #MEAction NOW. He must share his plan to increase funding and respond immediately to the millions suffering with ME. Your actions will drive urgency towards this meeting.

[Learn more](#) about #MillionsMissing

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](#)

If you would like to send shoes to a demonstration, here is the [list of locations](#) accepting shoes.

[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 and #CanYouSeeMEnow with the goal of demanding justice from our government.



Date

May 12th

Event Location

- Online / Your home

BEFORE May 12th

1. [Register](#) your individual event. Even if you are only one person 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."
2. Consider [purchasing](#) a t-shirt to show solidarity in branding.
3. Sign the [NIH petition](#) and [global petition](#), and spread the word asking friends and family to sign, as well.

If you would like to send shoes to a demonstration, here is the [list of locations](#) accepting shoes.

On May 12th:

- **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? / @NIH.gov !

Show your face. We are encouraging participants to take a photo of themselves this year to show the number of people afflicted with ME, similar to this photo from the BedFest campaign.



Of course, if you'd prefer to remain anonymous, you can take a photo of your shoes with a note expressing what you're missing.



This year, we encourage people to hold up one of the [posters](#) we've provided, **or** to make your own sign. If you make your own sign, consider including your location and the hashtags:

- #CanYouSeeMENow in Wilmington, North Carolina
- #MillionsMissing in Wilmington, North Carolina



Intimate (a few friends and family)



BEFORE May 12th

1. Choose an event location
 - Online
 - Your home
 - A friend / family member's home

2. [Register your event.](#)

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.

3. [Find a Co-Host\(s\) \(CHOOSE 1-6\)](#)

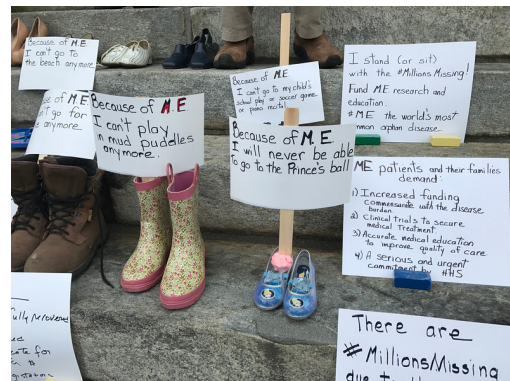
- Friends / family
- Local / state / regional #MEAction advocates
- ME or ally organizations
- Local ally organizations (example: local Lyme disease, Fibromyalgia groups, Disability groups, Women’s Rights orgs, etc.)
- Colleagues
- I’m doing this by myself (this is totally okay!)

4. [Get the Word Out](#)

- Set up a Facebook Event
- Post about your event on social media
- [Send invitations](#) to invite others to participate in your Visibility Action

5. [Determine your props \(CHOOSE 1-4\)](#)

- **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.



Consider creating a display like the person did in front of their home in the Netherlands. Print this [tag](#) to attach to the shoe.



- [Posters](#) - We have posters with a message directed at the NIH director / and an [editable poster](#) where you can indicate your location.
- [Handout](#)
- T-shirt - [purchase](#) #MillionsMissing t-shirts to show solidarity through branding

6. Spread the word

- Let others know about #MillionsMissing using posts from our [Social media toolkit](#), or create your own.

DURING your Event:

Program Options (Choose 1-6)

- 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
- Petitions - ask attendees to sign these petitions using their phones: [NIH petition](#) and [global petition](#)
- *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? / @NIH.gov !

Neighborhood / Community

BEFORE your event:

Event date

- May 12th

Learn from previous protests - [check out videos](#) from San Francisco / London / Syden / Denmark etc.

Register your event [here](#).

Note: For everyone, who registers an event, we will create a [calendar event](#) on #MEAction where people can RSVP. We add the person who registers as an administrator of the event so they can change anything on the event page themselves.

Choose an event location (CHOOSE 1)

- Online
- 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.*

Find a Co-Host(s) (CHOOSE 1-6)

- 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 the word out (CHOOSE 1-4)

- Set up a Facebook Event
- Post about your event on social media
- [Send invitations](#) to invite others to participate in your Visibility Action
- Advertise at your doctor's office or local coffee shop - [distribute this flyer](#) (copy and paste into a google document in order to edit).
- Reach out local press - see below.

Props (CHOOSE 1-5)

- **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 [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.

- [Posters](#) - We have posters with a message directed at the NIH director / and an [editable poster](#) where you can indicate your location.
- [Handouts](#)
- 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.

Publicity (CHOOSE 0-2)

- Post on Social Media about your event
- Advertise at your doctor's office or local coffee shop - [distribute this flyer](#) (copy and paste into a google document in order to edit).
- Reach out to local press using our [sample press release](#).

(Keep in mind that personalizing the press release to include local stories of people with ME is very powerful. Journalists are more willing to cover a human-interest story than a protest.

So, if a few people are willing to share their stories, include a few sentences in the press release about people attending the protest to give it a human touch.

For example, Emma Harrison of Witchita Falls is a 32-year-old mother of three who had to quit her job as an engineer, and is mostly housebound. Peter McKinsey takes care of his 12-year-old son who can only attend school a few mornings per week due to the illness.)

- Learn about how to talk to the press. Check out our [training guide](#).

During your event:

Program Options (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](#).
- Story Sharing
- Handouts: [Fliers](#) or brochure: About ME (general audience) – [inside](#) and [outside](#).
- Petitions - ask attendees to sign these petitions using their phones: [NIH petition](#) and [global petition](#)
- 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.

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? / @NIH.gov !

City-Wide

BEFORE your event:

Event date

- May 12th

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Learn from previous protests - [check out videos](#) from San Francisco / London / Syden / Denmark etc.

Choose an event location

- 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.*

Find a Co-Host(s) (CHOOSE 1-6)

- 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 the word out (CHOOSE 1-4)

- Set up a Facebook Event
- Post about your event on social media - **use the hashtags** #MillionsMissing and #CanYouSeeMEnow
- [Send invitations](#) to invite others to participate in your Visibility Action
- Advertise at your doctor's office or local coffee shop - [distribute this flyer](#) (copy and paste into a google document in order to edit).
- Reach out local press** (Your event should not be framed around getting press and there is no pressure to do so). See below.

Props

We encourage props at city-wide events to help attract attention from the public.

- **Shoes** - Shoes have been a powerful, unifying 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:

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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.

- [Posters](#)
- [Handout](#) or brochure - About ME (general audience) – [inside](#) and [outside](#).
- 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.

Publicity (CHOOSE 0-2)

- Post on Social Media - **use the hashtags** #MillionsMissing and #CanYouSeeMENow
- Advertise at your doctor's office or local coffee shop - [distribute this flyer](#) (copy and paste into a google document in order to edit).
- Reach out to local press using our [sample press release](#).

(Keep in mind that personalizing the press release to include local stories of people with ME is very powerful. Journalists are more willing to cover a human-interest story than a protest.

So, if a few people are willing to share their stories, include a few sentences in the press release about people attending the protest to give it a human touch.

For example, Emma Harrison of Wichita Falls is a 32-year-old mother of three who had to quit her job as an engineer, and is mostly housebound. Peter McKinsey takes care of his 12-year-old son who can only attend school a few mornings per week due to the illness.)

- Learn about how to talk to the press. Check out our [training guide](#).

Program Options (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](#).
- Story Sharing
- Petitions - Advertise ahead-of-time, or ask attendees to sign these petitions using their phones: [NIH petition](#) and [global petition](#)
- 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.

AFTER your event:

Follow up (CHOOSE 1-3)

- **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? / @NIH.gov

Press / Media Resources

- [Media Training Manual](#) (if you want to go above and beyond!):
- Press List: <https://drive.google.com/drive/folders/0Bz69XTIsVajYRW9ldFU4cGRma00>
- [Sample press release](#)

Resources:

- [What is #MillionsMissing?](#)
- Advertise your protest - [distribute this flyer](#) (copy and paste into a google document in order to edit).
- [Handout](#)
- Brochure - About ME (general audience) – [inside](#) and [outside](#).
- [Posters](#)
- [Tag](#) to attach to a shoe
- [Photo & Video tips](#)
- [Sample press release](#)
- [Merchandise](#) - purchase a t-shirt
- [Visual Ideas](#).