



# Massachusetts ME/CFS & FM

— ASSOCIATION —

EDUCATION, SUPPORT & ADVOCACY SINCE 1985

## VOLUNTEER ORIENTATION

### **Welcome!**

As a volunteer with the Massachusetts ME/CFS & FM Association you are now part of a group of caring, dedicated individuals who generously contribute their time and energy in order to help improve the lives of others.

Our organization is comprised of patients living with the debilitating effects of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia, as well as their families, friends, and allies.

This orientation will provide you with a sense of the Association's purpose, its organizational structure, and the programs and services that we offer.

On behalf of our members and the ME/CFS & FM community –

***Thank You!***

## OUR HISTORY

"When we started the first support group in 1983, I had no idea what this organization would grow into. These illnesses did not even have names, let alone any treatment options then."

— *Bonnie Gorman, Founder*



The Massachusetts ME/CFS & FM Association ('MassME') is one of the oldest voluntary ME patient associations in the United States, and has a long and productive history helping patients and their families, educating doctors and the public, and advocating for patients and medical research.

The Association was founded in 1983 to raise awareness about and help people cope with what is now known as Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). There was very little information available at that time. For decades our volunteers shuttled books and articles back and forth to home-bound patients on foot, by car or by US mail. Every article, VHS tape or news mention was a major event: a glimmer of hope for sufferers. We created a network of support groups where people could meet in person to share stories, share resources, and help one another cope.

The Association then began a long history of public education programs by sponsoring public lectures by doctors and other experts who were studying these illnesses and by providing information and services to patients. By 1988, the U.S. Centers for Disease Control and Prevention (CDC) had officially recognized Chronic Fatigue Syndrome as an illness (previously called Chronic Epstein-Barr Virus Syndrome). That same year, the Association officially incorporated as a tax-exempt, non-profit organization.

In 1991, MassME published and distributed the first physicians' primer to all physicians in Massachusetts and many patients and physicians around the world.

Since then, we have assisted thousands of patients in learning more about their illness, locating knowledgeable physicians, helping to file disability claims, facilitating support groups, and assisting people diagnosed with ME/CFS or FM to obtain the support needed to cope with their illness. During this period, our much-acclaimed newsletter *The Update* was published quarterly. Additionally, we produced a comprehensive Disability Handbook that is still used today and provides information regarding disability and other benefits for patients who become too ill to work.

For over twenty years, we have offered an Information and Support phone line staffed by volunteers. We've worked tirelessly with other national and regional support groups to obtain recognition of the illnesses as well as research funding from the federal government. In the mid-2000s MassME transformed its website into a portal for comprehensive information on the illnesses, and a guide to the many services offered. Our newsletter is now distributed monthly to a list of subscribers here in Massachusetts, across the US, and around the world. The Association continues to be well-known for its high standard of credibility in providing well-researched information about ME/CFS and FM and their treatments.

From its conception until just recently, the Association has been an all-volunteer Association.

**It is due to the dedication and generosity of patients and healthy volunteers like you that we've been able to persevere for more than 25 years.**

## **OUR MISSION**

To support persons living with ME/CFS and their families by connecting them to supportive resources and each other, and by working to improve the healthcare and services available through education and advocacy.

## **OUR SERVICES**

### **Communication**

MassME works to provide accurate, helpful, current information about ME/CFS and FM

- Website: The Association's Website offers a wide variety of content to educate patients, families, health-care providers, and the general public.
- Newsletter: A monthly e-newsletter offers highlights on related news, research, events, and more.
- Social Media: Find us on Twitter, Instagram, Facebook, and YouTube.
- Slack: The MassME Slack channel is open to volunteers and support group members, and is a place for conversation, information sharing, project work, and community.

### **Patient Services**

The core of our work is to connect Massachusetts residents with ME/CFS or FM to each other for mutual support, and to appropriate healthcare and service providers.

- Doctor Referrals: We help those newly diagnosed find appropriate and informed healthcare providers.
- Disability Counseling: We provide counseling and information on applying for disability, disability income, insurance, housing and other programs.
- Support Groups: MassME offers a range of support groups (currently all online) where those in the ME/CFS community can share experiences and knowledge.

### **Education and Advocacy**

The Association continually strives to expand recognition of ME/CFS & FM and to educate schools, healthcare providers, families and the general public.

- Medical and Public Education: MassME organizes lectures and events to bring information about ME/CFS to healthcare providers, medical students, and the general public.
- Social services advocacy: The Association provides a bridge between our members and other organizations that can provide needed services.
- Research and Legislative advocacy: We collaborate with other patient groups to advocate for further research in the hope of finding a cause, more effective treatments, and ultimately, a cure.

## How the Association Is Organized

As a new volunteer it is useful for you to know how your work contributes to the work of the overall organization.

**The Board of Directors** is legally responsible to direct the non-profit organization in accordance with the Association's Bylaws. The Board holds primary decision-making power for the Association, approves and adopts the Association's policies and programs, and authorizes funding of all expenditures.

**The Core Team** is comprised of Coordinators of our main programs – Patient Services, Legislative Advocacy, Events, Volunteers and Communication – as well as volunteers who are actively leading major projects. The Core Team designs and oversees the implementation of our programs.

**The Volunteer Coordinator** recruits, orients, and guides the volunteers who power the Association.

**You, the Volunteers** are the heart of our organization. You make up the Project Teams that enact our mission and sustain the organization. You make all this work. Every other month, volunteers will have the opportunity to meet with the Board, the Volunteer Coordinator and other volunteers to discuss new opportunities and to offer insights and suggestions.



## **OUR PLEDGE TO YOU AS A VOLUNTEER**

The Massachusetts ME/CFS & FM Association is committed to making your volunteer experience a rewarding and successful one. We pledge to:

- Provide the opportunity for you to make a meaningful contribution based on your interests, skills, and available time
- Give you a chance to get to know Association members and other volunteers if you are interested in doing so
- Allow you to participate further if you are so inclined
- Provide at least one contact person or mentor for guidance and support
- Offer encouragement and additional assistance as needed or requested
- Recognize and work within your boundaries and limitations, particularly if you are a person living with chronic illness
- *Recognize and appreciate your contributions*

## **WHAT WE ASK OF YOU AS A VOLUNTEER**

As a volunteer with the Massachusetts CFIDS/ME & FM Association, we ask that you:

- Do your very best to follow through with any commitments/tasks you undertake and let us know if you are unable to fulfill them in a timely manner
- Check your e-mail and Slack channels regularly, be responsive, and let us know if you cannot fulfill this request at any given time
- Make every effort to review materials (if provided) in advance of meetings, whether that meeting is in person or by conference call
- Join scheduled conference calls on time and let the meeting facilitator know in advance if you will be unable to do so
- Let us know if you are not finding your volunteer experience comfortable and worthwhile so that we may do our best to make adjustments to our mutual satisfaction

## The Advocacy Landscape

When the Association was founded in 1983 there was little information available about the illness now known as ME/CFS. Other state organizations were formed, but it wasn't until recently that organizations with broad advocacy and research agendas appeared. MassME maintains constructive and mutually beneficial relationships with many other organizations.

- **MEAction** is an international advocacy organization founded by Jennifer Brea (producer of the film *Unrest*). MEAction fights for recognition, education, and research, through grassroots organizing and distributed and networked learning. MassME participates in MEAction's annual #MillionsMissing event, and has hosted multiple screenings of *Unrest* for healthcare students, public health professionals, and the general public.
- **The SolveME/CFS Initiative** (Solve ME) serves as a catalyst for research into diagnostics and treatments for ME/CFS and other post-infectious illnesses. SolveME funds innovative research through grants, gathers data through a patient registry and biobank, and works to improve medical education about these illnesses. MassME works with SolveME on legislative advocacy, and participates the annual advocacy week on Capitol Hill organized by SolveME.
- **Open Medicine Foundation** (OMF) directly funds medical research to find effective treatments and diagnostic markers for chronic complex illnesses, with a focus on ME/CFS. MassME has collaborated with OMF on fundraising and medical education events, and works with the Harvard ME/CFS Collaboration to provide patient input and support.
- **The Long COVID Alliance** is a patient-centered network of advocates, scientists, healthcare providers, and experts pooling knowledge and resources to educate policy makers and accelerate research into post-viral illnesses. MassME was one of the founding partner organizations of the Long COVID Alliance.

## **Definitions and Acronym Guide**

### **ME/CFS**

Myalgic Encephalomyelitis (ME) also known in the U.S. as Chronic Fatigue Syndrome (CFS), is a complex, debilitating, and often disabling illness which affects multiple systems of the body. Most people with ME/CFS experience profound exhaustion, post- exertional malaise, sleep disorder, neurological and flu-like symptoms, and difficulty thinking. The illness may last many months or years. Symptoms may vary in severity and may wax and wane. The cause(s) have yet to be identified and there is no known cure. Scientific research has shown the illness to be a real, organic illness.

### **Fibromyalgia**

Fibromyalgia (FM) means “soft tissue and muscle pain.” The soft tissues are the tendons or ligaments. It is a chronic pain syndrome which is sometimes associated with ME/CFS and sometimes confused with it. The two illnesses are likely separate, although they can sometimes occur in the same person. The pain can be severe enough to interfere with routine daily activities. It migrates, can be achy, burning, throbbing, shooting, or stabbing, and is worse in areas used the most, like in the neck or back. FM is associated with “tender points” which are painful when pressure is applied to them. Two of the other most common symptoms of FM are sleep disturbance and profound exhaustion. Other symptoms include stiffness, memory and concentration problems, and headaches.

### ***Here are some of the more common acronyms you will encounter.***

**CDC** - Centers for Disease Control and Prevention (CDC), located in Atlanta, Georgia, is the government agency responsible for public health and answers to the Department of Health and Human Service (DHHS). CDC is called upon to investigate outbreaks, conduct research, develop health policies, and provide leadership and training among some of its many duties.

**CFS** - In 1988, the Centers for Disease Control and Prevention (CDC) published their definition of the illness in *Annals of Internal Medicine*, naming it Chronic Fatigue Syndrome (CFS). To say the name was a bit dismissive is an understatement.

**CFIDS** (pronounced “cee-fids”) – By the 1990’s, patient groups and patients started calling the disease Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) to reflect the immune component of the illness. However, the formal name for research in America is still CFS.



**FM** - In 1976, Fibromyalgia (FM) was first coined as a term, even though the illness had been believed to have been around for a long time. In 1990, The American College of Rheumatology developed diagnostic criteria for doing FM research and the term caught on.

**IACFS/ME** - Formerly called the AACFS, the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME) currently runs a biannual international scientific conference that brings together researchers from all over the world.

**ME** - In 1956, Dr. Melvin Ramsey, of England, coined the term Myalgic Encephalomyelitis (ME) while investigating an illness that had “CFIDS-like” properties. The name was first published in the United Kingdom in the “*Lancet*.”

**NIH** - National Institutes of Health, located in Bethesda, Maryland, is made up of many Institutes. Their mission statement reads “NIH’s mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability.” The various Institutes foster creative discoveries, develop innovative research, which, when applied, improves health. They have a rich history. They too are a division of the Department of Health and Human Services.

**pwME** - Person with ME. This person-first terminology has been adopted by the disability community to emphasize the individual’s right to be acknowledged as a full human being first, and place the illness or disability second. More recently disability advocates have embraced identity-first language – ‘disabled person’ or ‘ME/CFS patient’ – and the term pwME is seen less often. Note that the term ‘patient’ is seen as too medically-determined in other disability and illnesses, but in ME/CFS and FM advocacy this is complicated by the fact that we have had to fight for decades to be seen as legitimate patients of a biological illness, and the term is read as legitimizing rather than disempowering.



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We hope that this document has given you a basic understanding of the Association's history, purpose, structure, programs and services.

As you begin your work as a MassME volunteer, please do not hesitate to ask for information or assistance at any time.

We need the help of all volunteers to keep the Association running smoothly and to accomplish our mission. Remember, even a little time put together with the efforts of others can accomplish a great deal!

With Appreciation,  
The Massachusetts ME/CFS & FM Association

## **The Massachusetts ME/CFS & FM Association**

Information Line: 617-471-5559

Email: [info@massmecfs.org](mailto:info@massmecfs.org)

Website: [www.massmecfs.org](http://www.massmecfs.org)

Mailing address:

PO Box 690305

Quincy MA 02269