History of the Association

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Print

The Massachusetts ME/CFS & FM Association is one of the oldest voluntary associations in the United States for patients withMyalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS or CFIDS) and Fibromyalgia (FM) , and has had a long and productive history, helping patients and their families, educating doctors and the public, and advocating for patients and medical research.

Founding the organization

In the words of our founder, Bonnie Gorman, RN:

> “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. Now the Massachusetts CFIDS/ME &FM Association [as it was called at the time of these remarks] is the oldest patient support organization in the country [for these illnesses]. We expanded into a support group network in 1984, and started our education programs, something very dear to my heart. Ironically, we were still an informal organization in search of a name for our illness. It was then called the 'disease of a thousand names:' post-viral fatigue syndrome, chronic mono, neurasthenia, Icelandic disease, myalgic encephalitis, fibrositis etc.
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> In January of 1985, the publication of the, then, seminal article in *JAMA* finally gave our illness a new name (at least for the eighties)—Chronic Epstein Barr Virus (CEBV). That moved us to formalize our statewide organization and name it the Massachusetts CEBV Association. We also started our highly-acclaimed newsletter, *The UPDATE*, in 1985—continuing our mission of providing quality medical information to our members, the medical community and the general public. We then added our information line and lending library, followed by our physician referral and disability guidance. In addition we developed innumerable special programs over the years to better serve our members.
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> Our advocacy and public awareness campaigns followed at the state, regional and national levels. We were founding members of the first national CFIDS advocacy campaign, CACTUS. Our organization has pioneered many critical issues through our advocacy campaigns—giving voice to those with CFIDS & FM."

Legally named Massachusetts C. F. I. D. S. Association, the organization has updated its “doing business as” name periodically, adding Fibromyalgia (“& FM”) in the early 1990s, changing “CFIDS” to “CFIDS/ME” in 2008, and “CFIDS/ME” to “ME/CFS” in 2018.

Celebrating our 25th year

In April 2010 we presented an award to Bonnie Gorman, R.N., a founder of the Massachusetts CFIDS/ME & FM

Association. In this short video, Bonnie recounts the early history of the Association, the first voluntary patient association for these illnesses even before they had a name. She tells how, from a single support group begun in 1983, it quickly grew to become a resource for similar groups across the nation, and to provide the wide range of service, support, and education we offer today.

View the video (/images/videofiles/Gorman/Gorman.mp4).

More about us

Our accomplishments (/accomplishments-of-our-association)

Our ongoing programs (/our-on-going-programs)

Patient services (/services)