

Massachusetts ME/CFS and FM Association

Strategic Plan

June 2020



Massachusetts ME/CFS & FM
ASSOCIATION

EDUCATION, SUPPORT & ADVOCACY SINCE 1985



Table of Contents

Executive Summary

1.0	Introduction.....	2
1.1	Purpose	
1.2	Contents	
2.0	Current Situation	3
2.1	History	
2.2	Structure	
2.3	Programs	
2.4	Finances	
2.5	Culture	
2.6	Challenges	
3.0	Defining Our Future.....	7
3.1	Mission	
3.2	Pillars	
3.2.1	Mutual Support	
3.2.2	Medical Education	
3.2.3	Service Advocacy	
3.3	Sustainable Organization	
4.0	Projects and Priorities	12
4.1	List of Projects	
4.2	Priorities	
5.0	Next Steps	23
	Appendices	24
	Strategic Plan Pre-work	
	Facilitated Session	
	Plan Development	



Executive Summary

The Massachusetts ME/CFS and FM Association (MassME) is the oldest continuously running state organization supporting and advocating for ME/CFS and FM patients. Over our thirty-year history we have continually reevaluated and refocused our activities according to the changing landscape of medical knowledge, of national and international advocacy organizations, and the needs of our members. In 2019 a committee was convened to take stock of our resources and establish clear priorities and actions for MassME.

Main Recommendations

- Focus on services to patients in Massachusetts
- Support (but not necessarily lead) national efforts in advocacy and visibility
- Don't try to reproduce what other organizations are better positioned to do

With this strengthened focus, the committee established four 'pillars' of the organization, and defined clear projects that MassME could undertake in the next few years to support these four pillars:

Support people and their families

- Improve website information
- Expand support group options
- Increase confidence in doctor referrals

Educate healthcare providers

- Increase the number of ME/CFS knowledgeable primary care physicians and other healthcare providers interested in working with patients in MA

Advocate for social services

- Understand and document the social service needs of ME/CFS patients in MA
- Educate MA social service providers about ME/CFS
- Build social service support capacity

Sustain the Association

- Double membership
- Fill all leadership positions
- Fully fund the operating budget commensurate with this strategic plan
- Support national efforts where we can



1.0 Introduction

The landscape of ME/CFS has changed radically from when our organization began in 1985. This strategic plan sets a course for the Massachusetts ME/CFS & FM Association for the next five years. This is the future we imagine for ourselves.

1.1 Purpose

2018 and 2019 were extremely busy years for the Association. We held eighteen public information events throughout the state, reaching an audience of over 1500 people, including dozens of doctors and other health care providers. We fielded over 200 requests for assistance to locate health care providers and social services for patients, requiring hundreds of hours of telephone, on-line and in-person support. We lobbied our legislators at both state and national levels, participated in #MillionsMissing in Boston, attended national ME/CFS Lobby Day and the NIH research update in Washington DC, finalized curricula for the nation's first accredited course in ME/CFS for school nurses, and much more. While we accomplished a lot, the hectic pace took a toll on the health of our volunteers and stretched the limits of our organization beyond our level of comfort. We recognized the need to re-focus and set new and clear priorities in order to maintain our own and the Association's effectiveness.

With our full-time President planning to step down at the end of 2018, a group of volunteers and Board members spent the summer of 2018 investigating how our organization could manage a growing demand for our services without a full-time healthy volunteer leader. The principal recommendation was to establish an organizational structure that allows separation between matters of governance and daily operations. Governance would become the principal responsibility of the board, while operations, or program execution, would become the responsibility of a new group of committed and organized volunteers. In November 2018 the Association elected a new slate of officers and added four new board members. The new Board approved the recommendations and immediately initiated a strategic planning process to chart a course for the future.

1.2 Process

This strategic plan was developed in four stages. In stage 1, the Board established a scope of work for the planning process, invited non-board members to participate and established a timeline for the work so that a draft plan could be available for the annual Fall meeting of the Association. Each member of the planning team identified a list of concerns, a list of ideas and a statement of personal goals.

In stage 2, a professional facilitator was engaged to conduct three on-line work sessions. Session 1 addressed the role of the Association in the larger landscape of ME/CFS organizations nationwide. A draft mission statement was crafted recognizing the history and assets of the Association, the concerns and ideas of participants and the responsibilities of a statewide Association. Session 2 established the operational foundation of the Association, referred to herein as "pillars."



Session 3 established a preliminary set of priorities for each pillar. A subset of planning group members reviewed all the notes and documentation produced in stages 1 and 2 and created a list of projects and activities, collectively considered necessary and sufficient to meet the mission and fulfill the operational priorities of the pillars.

In stage 4, projects were prioritized by the larger group. This final document was drafted, reviewed, edited and published.

1.3 Contents

Section 2 describes the history and current operations of the Association. Section 3 presents the future strategy. Section 4 presents the operational priorities. Section 5 discusses the steps required to implement this plan. The Appendix includes all notes and documents established throughout development of the plan.

The document may be read in paper form; however, access to the full set of references and attachments requires an internet connection.

2.0 Current Situation

This section provides background on the Association's history, current structure, operations, financial position and challenges.

2.1 History

The Massachusetts Chronic Epstein Barr Virus (EBV) 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. There was no internet. 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 meet in person to share stories, share resources and help one another cope. We enjoyed a warm collaboration with one of our nation's ME/CFS heroes, Anthony Komaroff, who sat on our medical advisory board and provided yearly updates to our members at our annual conference. It was a time when Dr. Komaroff could not find an audience of fellow physicians who had any interest in the illness.

Our Association has changed names over the years, changes that have kept pace with recognized medical advances in understanding the illness: from Chronic EBV to Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) to our current name, the Massachusetts ME/CFS & FM Association, Inc. In the 1990's we added fibromyalgia to our name and mission.



Our Association has endured for over three decades. It is widely believed that we are the oldest ME/CFS patient association in the United States. In the beginning, we were one of the only associations. We've blazed the trail that has led to the ME/CFS community of today. We are no longer a lone voice in the wilderness. Influential and well-funded national organizations seek the support of our Association for activities that affect Massachusetts patients and physicians. Indeed, Dr. Komaroff now commands an international audience! In this new era of ME/CFS research, dialog and international coordination, we are now part of a much larger landscape. The strategic planning process has helped us to understand our place within it and to plan our work for the future.

2.2 Structure

The Association is a 501(c)3 charity registered in the Commonwealth of Massachusetts. Membership is open to patients, their friends and families, and allies who support the goals of the Association. A President is the chief executive and also the Board Chair. The membership of the Association elects a slate of Board members in November, at the annual business meeting, for a two year term. The Board then elects its officers: President, Vice President, Treasurer and Clerk. The work of the Association is carried out by committees. While everyone in the Association is a volunteer (there are no paid staff), the term "volunteer" is typically used to connote non-board members of the Association who volunteer their time to conduct committee work under the direction of a committee head. Until very recently, all committees were headed by a member of the board. Historically, outside professionals have been engaged by the board for information technology (IT) maintenance and development and for event coordination and production.

2.3 Programs

Historically our mission has been to improve the lives of all people affected by ME/CFS and FM, advancing awareness, care, treatment and research. We worked to improve the lives of ME/CFS and FM patients **indirectly**, by helping to make advances in the areas of awareness (of the diseases), care/treatment (of persons living with these diseases) and advocating for research.

Milestones in History

- 1983 Started a support group in Massachusetts for the "unnamed illness"
- 1985 Incorporated Massachusetts CEBV Association as a 501(c)3 organization
- 1986 Began publication of a hard-copy newsletter, "The Update"
- 1987 Changed name to Massachusetts CFIDS Association
- 1990 Established Medical Advisory Committee
- 1990 Grew support group network to 36 groups throughout New England
- 1992 Published the first-ever "primer" for clinicians
- 1995 Published first version of the Disability Handbook
- 2009 Introduced new, revised website
- 2010 Began school nurse education program
- 2017 Initiated educational events aimed at healthcare providers and the public, using the film "Unrest"
- 2019 Changed name to Massachusetts ME/CFS & FM Association, Inc.



The Association provides information to the general public on a wide variety of topics relating to the illnesses through a website, Information Telephone Line and email newsletter. The newsletter distributes current ME/CFS & FM related news including information about events, conferences, lectures, recent articles, new research findings and more. There are 2,400 individuals on our mailing list, about half of whom are from Massachusetts. Roughly 30% of our mailing list includes individuals from states other than Massachusetts and 20% are from other countries.

The Association provides a range of services for patients, including physician referral, disability counseling, support group referrals and peer-to-peer counseling. Most of the support services are delivered to individuals in Massachusetts; however, assistance is also provided to those outside the region. The association receives and responds to roughly 200 requests per year.

The Association is developing new ways to educate and engage Massachusetts healthcare providers in serving the needs of ME/CFS patients. This work includes provider workshops, general information events and targeted training. The Association conducts legislative advocacy in Massachusetts, and coordinates with national organizations in advocacy efforts both on the regional and national levels.

Current Focus

- Advocate for research and advances in clinical care.
- Provide helpful information to patients and families.
- Implement general awareness programs for healthcare providers and the public.

2.4 Finances

In the years beginning in 2012, the Association has received several large donations: a corporate Community Giving grant, a legacy, and two large individual donations. At the same time, we began an annual fund-raising program. During this period, our expenses were modest, ranging from \$9,000 to \$13,000 per year. At the present time, the Association has \$146,000 in assets, most of which is liquid. Thus, present cash assets are adequate to fund nearly 10 years of operations under current conditions. The Association owns no equipment (with the exception of a single PC and projector) and operates using a virtual office and post office address. All volunteers conduct work using their own equipment and personal space. Volunteers are reimbursed for direct expenses, such as travel and expendables. Cost-equivalents for home office or other incidentals are not recorded, nor are labor hours. A rough estimate of volunteer labor hours, including board members, is 4,000 hours/year or approximately 2 full-time equivalents.

2.5 Culture

The core of the Association is and has always been individuals with the illness who volunteer their time to ease the burden of others. The Association strives to share knowledge, provide hope and restore dignity. Efforts are made to ensure that all programs and activities in some way address the common struggles faced by individuals living with the illness. Because the Association is made up of patients and their friends and family members, there is a culture of



inclusiveness and empathy. The Association is committed to a culture of respect for people of all abilities, races, genders, sexual identities and faiths. The Association enjoys an outstanding reputation for its commitment to patient education and support and for its enduring values of clarity, reliability, compassion and hard work. Despite our local (Massachusetts) focus, the Association is recognized internationally as a reliable and influential player in the ME/CFS community.

2.6 Challenges

The lack of ME/CFS knowledge among doctors, social services, nursing and public health communities is the single biggest obstacle to easing the burden of those living with ME/CFS. And the lack of actionable research frustrates progress at every level. Understanding the internal challenges currently faced by the Association is the first step to setting a course to combat these obstacles. Three main challenges stand out:

1. **We are an all-volunteer Association.** The majority of our volunteers are patients. Being sick, our capabilities wax and wane and we are subject to all the challenges of reliability, endurance, predictability, and concentration. More and more of our volunteers have family members with ME/CFS. Most of these volunteers work full time while caring for their family member and somehow manage to find time to do work with the Association. To continue our work we must create a stable workforce even if that requires moving beyond our “all-volunteer” model to include full or part-time paid staff.

We need dedicated volunteers who are committed to our mission, and are available and able to give enough time over a long enough period to help us complete the projects they take on. We need leaders as well as doers, but everyone should enjoy working with others toward a common goal.

2. **We are a geographically based Association.** While much can and must be done in Massachusetts, we alone are not going to create a biomarker, find a cure, or create standardized diagnosis codes for health insurance. To attack these problems, we must continue to work with like-minded organizations with complementary missions. In the past several years, other organizations with a national purview and mission (MEAction, the Open Medicine Foundation, Solve ME/CFS Initiative) have taken leadership roles in legislative advocacy, public education, direct funding of research, patient education and internet-based community-building among patients and their families. We must find ways to share resources and coordinate activities so that our actions in Massachusetts are aligned with and benefit from actions nationally and internationally.

We need national partners to advocate for more funding for research, push our federal health agencies to increase their commitment to ME/CFS, and work with Congress to ensure that funding for ME/CFS activities is included in the federal budget.



- 3. **Our communications infrastructure is old.** The software tools the Association relies upon are several generations old and we have little experience with social media. This limits our outreach ability and constrains the frequency and quality of our messaging. It limits the degree to which interested individuals can learn about the Association and/or access the high-quality ME/CFS information we have on our website. It also limits opportunities for engagement among current and potential future members and donors.

We need to refresh our website, optimize our content for mobile and social media, and carry out compelling communication with our members and supporters.

We need to modernize our communications infrastructure and methods so we can share our progress and engage more fully with our members, supporters and the community.

3.0 Defining Our Future

3.1 Mission

Education, patient support, awareness-building and advocacy have been and will always be a part of what we do. But the needs are seemingly limitless. The more we learn about ME/CFS, the more starkly visible the challenges: the desperate circumstances of so many patients, the lack of diagnostic tests, the lack of proven treatments, misinformation among health care and social service providers and the massive gap between research needs and research funding.

Our new Mission statement is intended to set the boundary around those limitless needs; a boundary within which we believe we can most effectively serve the Massachusetts ME/CFS community. It is intended to inform and guide our work. It focuses our work primarily on activities that will **directly** help persons living with ME/CFS (and FM) in Massachusetts, putting less emphasis on our historic focus on advocacy and public education.

Our mission is 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.

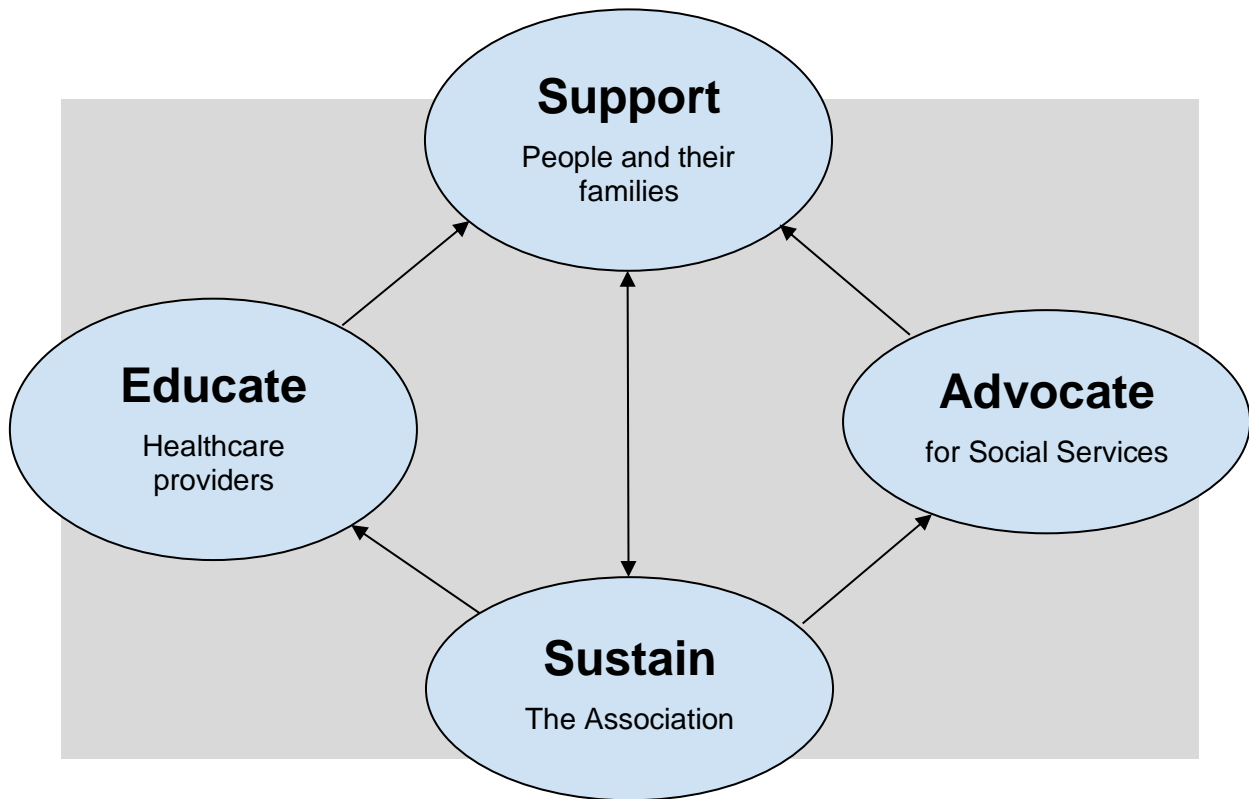
Our programmatic and organizational priorities are determined through direct member input, guided by best practice and our values of clarity, reliability, compassion and usefulness.

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.



- We are a “home base” for people affected by ME/CFS, providing opportunities for members to support one another; share knowledge, advice, information and hope. (Mutual Support)
- We raise awareness of ME/CFS among healthcare professionals with the goal of increasing the pool of knowledgeable providers available to diagnose and treat individuals in Massachusetts. (Medical Education)
- We build relationships with support service agencies so that we can effectively advocate for the needs of our members and increase the service providers’ capacity, willingness and effectiveness in working with ME/CFS patients. (Service Advocacy)
- In order to fulfill our mission, we must remain a healthy organization, with sufficient human resources to complete our projects and govern our Association, and sufficient funding to meet our expenses with some reserve for the future. (Sustainable Organization)



3.2 Pillars

Our mission is supported by four pillars: (1) mutual support; (2) medical education; (3) service advocacy; and (4) sustainability. The first three may be considered the services we provide (how we “do” our mission), the latter is what we must do to keep our Association financially and emotionally healthy.



3.2.1 Mutual Support

We strive to share knowledge, provide hope and restore dignity to individuals struggling with this dreaded disease. Our current mutual support related activities include our Doctor Referral Program, the Peer Support Group, Disability Counseling and ad-hoc

There are approximately 28,000 ME/CFS patients in MA. Yet the Association has only 200 or so members and a mailing list of less than 2,000. Are we providing adequate support?

Strategic Priorities

- Improve website information access
- Expand support group options
- Increase confidence in doctor referrals

communications that connect individuals seeking advice with others we know of that might provide that advice (see [details](#)). Historically we have referred to these activities as *patient services*. Although we are not doctors, we have extraordinary institutional knowledge which we share freely as a means of mutual support. Individuals we support become volunteers who support others. Our database of doctors and their specialties is a valuable resource for making thoughtful referrals to those seeking health care. Maintaining database currency and integrity is critical to our mutual support pillar.

ME/CFS patients, their families and caregivers most often ask us for very specific services:

- information to help them successfully engage and negotiate with the healthcare system
- guidance and assistance with the disability process
- home care services for the severely ill
- contact with others in similar situations to relieve isolation, exchange information, and provide hope (e.g. support groups)
- easy access to the Association’s array of information

The Peer Support Group (PSG), started in 2018 by three young members with ME/CFS embodies the nature of our mutual support pillar. These individuals were introduced to the Association through the doctor referral program and met one another at Association events. They saw the need for a support group that did not require travel and that focused on individuals within the same geographic area. Looking to the future, we intend to provide more opportunities for patient-to-patient communication and mutual support, improve access to self-service information on our website and refresh our doctor database.

3.2.2 Medical Education

We have been working with school nurses for many years, helping them identify and provide appropriate services to children with ME/CFS. Our work has evolved into a national nurse education program that provides continuing education credits through an [on-line course](#). We have contributed to educational research papers such as the [Primer for Clinical Practitioners](#), [the Pediatric Primer](#) and the [2019 article](#) entitled Estimating Prevalence, Demographics, and Costs of ME/CFS Using Large Scale Medical Claims Data and Machine Learning.



Between Fall 2017 and Spring 2019 we held a series of UNREST viewings, each of which included a post-viewing panel discussion with doctors, researchers, people with ME/CFS and

The number of MA healthcare providers who know enough about ME/CFS that we can confidently recommend them to patients is very limited -- perhaps 30, in primary care and all specialties. It falls largely on the patient to assemble a health care "team" on their own, and to educate these providers about ME/CFS.

advocates. While our intent was general awareness-raising, we quickly learned that health professionals were attending our events and many of them have been greatly moved by what they have learned ([see details](#)).

Looking to the future, we intend to conduct trainings for primary care physicians by engaging directly with professional medical societies and medical education providers. We also intend to support the Open Medicine Foundation (OMF), the Harvard Hospitals Collaborative ME/CFS Research Program and UMass Medical Center to establish ME/CFS clinical centers in Massachusetts.

Strategic Priority

- Increase the number of ME/CFS knowledgeable primary care physicians interested in working with patients in Massachusetts.

3.2.3 Service Advocacy

In the early 1990's, long-time Board Member and past President Ken Casanova wrote a [handbook](#) for individuals with ME/CFS. The first of its kind in the nation, it has been updated several times and remains a valuable resource to patients and families. Decades of experience providing disability counseling has exposed us to the difficulties - indeed, tragedies - endured by some people with ME/CFS. In the last two years, the number of

Many social service agencies already exist in Massachusetts which could provide needed services to ME/CFS patients (Mass. Rehab. Commission, Visiting Nurse Association, elder care agencies). Our members may be unaware of help that could be made available.

requests for guidance and assistance addressing social service needs has increased dramatically. Our experience shows that social service providers lack the knowledge of ME/CFS that would prepare them to adequately address patients' needs.

Last year, we initiated a training program for members of the Massachusetts Rehabilitation Commission (MRC) in order to educate them about ME/CFS and better position them to address the needs of the ME/CFS community. Looking to the future, we intend to embrace service advocacy as a strategic pillar. We will work with service providers to build the capacity and knowledge needed to effectively serve ME/CFS patients.

Strategic Priorities

- Understand and document the social service needs of ME/CFS patients
- Educate social service providers about ME/CFS
- Build social service support capacity



Our priorities include expanding our programs with MRC and developing similar programs with other agencies (e.g., the Massachusetts Centers for Independent Living, VNA, etc). We will engage one or more social service professionals to help us target our outreach, and to review and validate our educational materials.

3.2.4 Sustainable Organization

2018 and 2019 have been extremely busy years for the Association. The level of activity took a toll on our volunteers and led us to recognize that the structure and operations of our Association is limiting our effectiveness and putting at risk the health of our volunteers. We determined the need to re-focus Board activities on traditional matters of governance while developing an operational structure that can execute the work of the Association ([see](#)

[details](#)). We also implemented term limits and succession steps for board members. While we hold the same values we had 35 years ago, our mode of operation needs to change. Looking to the future, we will consider moving from an all-volunteer to a “mostly” volunteer organization by hiring our first paid staff person and establishing on-going fundraising in support. We will also be recruiting volunteers to serve in non-board, operational roles, and engaging members directly in vetting this strategic plan and participating in its implementation.

In addition, we are committed to updating and increasing our fundraising efforts for the purpose of sustaining and growing the organization. We intend to 1) better engage with our donors to understand their needs, desires, and reasons for their investment in our mission, 2) increase our donor pool and 3) increase fundraising opportunities.

In 30 years our organization has gone through periods of enthusiastic participation followed by periods where there were only a few people to keep the Association going. We have had minimal bank balances, and windfalls. At the moment we have a healthy bank account and a good number of volunteers, but few “leaders” and a shrinking Board. We are now the only strong state ME/CFS organization remaining, and we have an excellent reputation that we would like to maintain.

Strategic Priorities

- Double membership
- Fill all leadership positions
- Fully fund the operating budget commensurate with this strategic plan

3.3 Strategy

We have a grand vision to make Massachusetts an ME/CFS friendly state. No other organization is in a better position to pursue such a goal and we must step up to this challenge if we are to remain relevant. Strategically, we must test all our investments and initiatives against our mission statement. We must work with like-minded organizations, sharing resources and pursuing goals with disciplined adherence to our pillars.

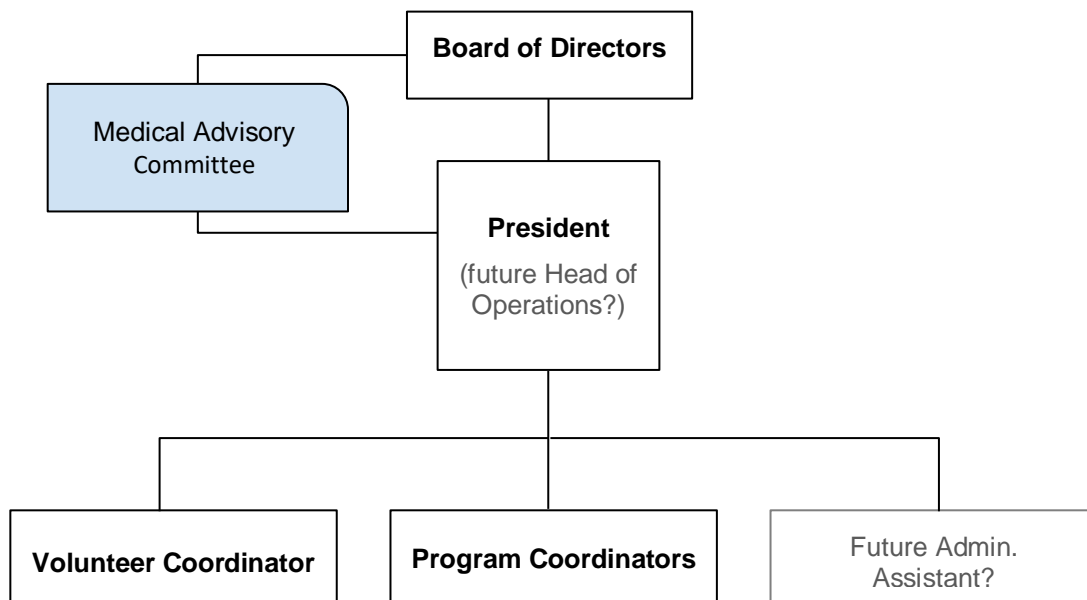
Taking stock of our mission and pillars, we intend to pursue the following strategic goals for the next two (2) years:



1. Improve information access for members, health care providers and the general public
2. Expand opportunities for peer-to-peer support
3. Improve the currency and reliability of our doctor referral database
4. Increase the number of ME/CFS knowledgeable physicians interested in working with patients in Massachusetts
5. Understand and document the social service needs of persons with ME/CFS, and work with providers in Massachusetts to expand their understanding and capacity to help
6. Engage more volunteers in Association activities
7. Implement the Association's new operating structure

4.0 Projects and Priorities

In this Section we identify the projects that are collectively necessary and sufficient to achieve the mission of the Association. This Section also identifies those projects that are a priority for the Association for the next two years and identifies project responsibilities based upon a new organizational structure, illustrated here. Background on this structure, including roles and responsibilities may be found in the Appendix.





Projects are a group of tasks that advance one or more strategic priorities. Projects require input from several staff and/or volunteers with a written scope of work, review process, start date, end date and deliverables (i.e., something someone needs to figure out how to get done and to manage). Many of the projects include activities that are ongoing while others are new initiatives.

4.1 List of projects

Table 1 (next page) lists the projects, the two-year goals they address and the presumed responsible party. The numbering system and order of the projects reflects the pillar under which the project was originally conceived.

The projects are described and discussed below. The description and scope of each project is not binding, and may vary according to circumstances as they are implemented.

1.1 Doctor Database Update

This project will refresh the database of doctors used by volunteers to make doctor referrals. The scope of work includes:

- Eliminating doctors no longer in practice, or no longer active with ME/CFS patients
- Expanding provider categories to include more nurse practitioners and non-medical health care practitioners
- Consolidating patient comments about doctors and making room in the database for new comments
- Seeking out information on providers from sources other than our membership and establishing criteria for including them in the database

1.2 Small Group Connection Program

This project will establish a template for small group gatherings among Association members. The scope of work includes:

- Reviewing lessons learned from prior small group gatherings
- Identifying topics and hosts for gatherings
- Managing the logistics of gatherings, collecting insights and feedback from hosts and participants
- keeping the board apprised of member needs and suggestions

It is anticipated that the first few gatherings will be focused on review and feedback on the strategic plan.



Table 1: Projects, Goals and Organizational Responsibility

Project/Activity	Two-year Goal						
	Support Information Access	Support Opportunities	Doctor Database	Social Services More PCPs	Engage More Capacity	Implement More Volunteers	Implement Operations
Mutual Support							
1.1. Doctor Database Update			✓	○			
1.2. Small group connection program		✓	○	○		○	
1.3. Support group program		✓					○
1.4. Doctor referral feedback		○	✓	○			
1.5. Handling Complex Support Group Requests			✓			○	
1.6. Website Improvements	✓	○	○			○	○
Medical Education							
2.1. Revitalize MAC			○	○		○	✓
2.2. Education Program for PCPs			○	✓	○	○	
2.3. Conduct Training Sessions for PCPs			○	✓	○	○	
2.4. ME/CFS Clinical Center			○	✓	○	○	
2.5. Student Internship			○	○	○	○	
Service Advocacy							
3.1. Expand Program With MRC			○	○	✓		
3.2. Conduct Study on ME/CFS Patient Support Needs		○	○	○	✓	○	
3.3. Develop Program with Other Social Service Agencies		○	○		✓	○	
3.4. Advocacy Coordination	○	✓		○	○	○	
3.5. Social Services Member Survey	○	○	○	○	✓	○	
Sustainable Association							
4.1. Volunteer Recruitment, Education and Recognition Program		○	○			○	✓
4.2. Communications Plan	✓	○	○		○	○	
4.3. Partnership Development	○	○	○	○	○		
4.4. Fill Leadership Positions	○	○	○	○	○	○	✓
4.5. Paid Staff Analysis							✓
4.6. Fundraising Program	○	○	○	○	○	○	✓
4.7. Membership Drive	○	○	○	○	○	✓	○
4.8. Collaboration With Other Chronic Illness Organizations	○	○	○	○	○	○	○
<p>✓ - The primary goal fulfilled by a project. ○ - Secondary or incidental goal fulfilled by a project.</p>							



1.3 Support Group Program

This project will establish a decentralized, sustainable mutual support program. The scope of work includes:

- Reviewing lessons learned from the Peer Support Group leaders
- Reviewing the future plans and current activities of national support groups
- Designing a process to establish official Association support groups
- Making tools, information and training available to support group hosts
- Collecting insights and feedback from hosts
- Keeping the board apprised of member needs and suggestions

1.4 Doctor Referral Feedback

This project will collect feedback from individuals who have utilized the doctor referral program. The scope of work includes:

- Reviewing past efforts to obtain feedback and determining why they have been unsuccessful
- Designing a method for obtaining feedback
- Implementing the feedback protocol
- Documenting feedback received

1.5 Handling Complex Support Requests

This project will train volunteers in handling support requests from individuals presenting with desperate circumstances, including suicide. The scope of work includes:

- Reviewing the Association's recent history responding to complex support requests
- Characterizing the nature of requests that are outside the comfort zone of our volunteers
- Identifying and hiring a professional (individual or organization) to offer advice and guidance to the Association on how to appropriately address complex support requests
- Preparing a response protocol for requests from individuals presenting with desperate circumstances

1.6 Refresh Website

This project will refresh the Association website to provide easier access to critical information for patients and their families. The project will be done in coordination with Project 4.2 (Communications Plan). The scope of work includes:

- Designing the website to meet the communications needs identified in the communications plan
- Identifying content categories and owners
- Creating a navigation design that makes current and important self-service information easily accessible and searchable, including at a minimum:
 - patient, family and caregiver education resources
 - requests for support group participation
 - doctor referral requests



- volunteer opportunities
- educational resources for primary care physicians
- educational resources for social service providers
- upcoming events
- Making it simple to donate to the Association

2.1 Revitalize MAC

This is a must-do project. Without it, the Association will not be able to support its work under the medical education pillar. The project will revitalize the Medical Advisory Committee (MAC), ensuring that certified health professionals are guiding, approving and enabling Association activities involving health care education and patient support. The full scope of work for this project may be viewed [here](#). It is summarized as follows:

- Establish MAC as an operating entity of the Association with a representative on the Board of Directors
- Populate MAC with board certified professionals in a range of health professions
- Establish a plan for regular communication to Massachusetts health professionals, with emphasis on primary care physicians. The plan should include:
 - Source of recipient list(s)
 - Communication medium (email, mail, social media, presentations, meetings, etc.)
 - General description of content of communications

2.2 Education Program for PCPs

This project provides ME/CFS education to primary care physicians in Massachusetts. The scope of work includes:

- Exploring interest among medical organizations through in-person meetings, including but not limited to:
 - Massachusetts Medical Society
 - Community Health Centers (through the Department of Health)
 - UMass Medical Center (Liisa Selin is interested in developing an ME/CFS clinical center)
- Holding discussions with physicians who attended and offered support during UNREST events
- Reviewing existing curricula including that provided by Medscape, CDC and Bateman-Horne;
- Exploring education approaches with NEUSHA, and the U.S. ME/CFS Clinician Coalition;
- Developing a training strategy for approval by the Board

2.3 Conduct Training Sessions for PCPs

This project follows project 2.2. It requires implementing the PCP training program strategy. The scope of work includes:

- Identifying up to four (4) venues at which to conduct trainings



- Preparing training materials and agenda
- Conducting trainings

2.4 Help Establish ME/CFS Clinical Center in at UMass Medical Center

This project provides direct support to Liisa Selin to create an ME/CFS clinical center at UMass. This involves working in a consulting capacity to:

- Research clinical care models at Bateman-Horne and other (past or present) clinical centers in the US
- Identify patient needs based on Association experience with physician referrals
- Determine opportunities for collaboration with the Northampton Integrative Medicine Center and/or the U.S. ME/CFS Clinician Coalition
- Determine what fundraising efforts may be needed
- Providing ad-hoc assistance at Liisa's request

2.5 Student Internship

This project will establish an internship program for students in Massachusetts interested in health care and the needs of ME/CFS patients. The scope of work includes:

- Identifying Association activities and projects suitable for and likely to be desirable to medical students
- Exploring interest with school administrators involved in student career counseling and internship placement
- Exploring funding and marketing opportunities with the Blue Ribbon Foundation
- Determining appropriate financial compensation for interns
- Marketing the program and selecting the first intern(s)

3.1 Expand program with MRC

This project continues our training program with the Massachusetts Rehabilitation Commission. The scope of work includes:

- Reviewing feedback from our first training session
- Establishing goals for up to three additional training sessions
- Preparing training materials and agenda
- Conducting trainings
- Working with MRC to produce a case study of MRC support to an ME/CFS patient for potential publication

3.2 Conduct study on ME/CFS patient support needs

This project will produce and publish a research study on the social service needs of ME/CFS patients in Massachusetts. This project will be funded and managed by the Association and contracted to a qualified research organization. The scope of work includes:

- Identifying qualified firms or independent researchers
- Preparing a request for proposal
- Reviewing, proposals, selecting a provider and negotiating a contract
- Managing the contractor



- Recommending actions for the Association to take based upon the findings of the study

3.3 Develop Program With Other Social Service Agencies

This project would expand our training program with MRC to include the Visiting Nurse Association, the Massachusetts Centers for Independent Living and other organizations that may be identified in Project 3.5, Social Services Member Survey.

3.4 Advocacy Coordination

This project continues our legislative advocacy, with an emphasis on collaboration with our advocacy partners as identified in Project 4.3, Partnership Development. Our annual Washington advocacy and MillionsMissing activities will be conducted under this project.

3.5 Social Services Member Survey

Document social service needs and set priorities accordingly. This project includes three parts:

1. Review research and advocacy literature to see if such studies already exist (focus on U.S.)
 - a. Search PubMed
 - b. Search advocacy sites such as #MEAction, Solve M.E., and blogs such as Health Rising
 - c. Query advocacy organizations such as #MEAction, USAWG
2. Put together a simple survey asking about needs and send it out to our constituents (via newsletter, FB, Twitter, announce at meetings, etc.) Survey would have an option to be anonymous, or respondent could provide name/email if they were willing to be contacted for more information.
3. Follow up with specific individuals to get more details (stories, "color") to use when preparing for meetings with the agencies.

Based on the results of the survey, we would then proceed to research and identify which social service agencies in MA to target under Project 3.3. It is anticipated that this be a one-person project.

4.1 Volunteer Recruitment, Education and Recognition Program

This project will create a comprehensive plan for attracting, managing and celebrating our volunteers. The scope of work for this project includes:

- Review practices of other organizations dealing with chronic illness or rare diseases
- Review for currency and relevance existing volunteer related documents, which include:
 - The volunteer database
 - Recruitment and interview form
 - Volunteer orientation booklet
 - Volunteer job descriptions
 - Work and function of volunteer committee



- Ensure volunteer outreach messaging is included in the communications plan (Project 4.2)
- Compile volunteer benefits and appreciation stories for sharing
- Recommend volunteer management policies to the Board

4.2 Communications Plan

This project will review and make recommendations to improve the Association's communications infrastructure and messaging practices. This project will be funded and managed by the Association and contracted to a qualified firm. The scope of work includes hiring a qualified individual or firm to perform the following scope of work:

- Review this strategic plan to understand the changing mission and priorities of the Association
- Review current communications infrastructure and practices, including:
 - Telephone information line, contact us form and request fulfillment
 - Newsletter signup, preparation, dissemination, and list management
 - Facebook and Twitter utilization
 - Outreach to, management of and communications with volunteers
 - Internal Association communication practices, including email and document management
 - URL domain and website management
- Review historical website traffic and page view statistics
- Conduct a survey of Association members to learn about their communications expectations and priorities
- Make recommendations for:
 - Nature, frequency and content of communications to best serve the Association and its members
 - Nature, frequency, content and audience for acquisition of new members and new sources of donation
 - Communications Infrastructure changes or upgrades
 - Software tools or subscriptions services that might better meet the needs of the Association

4.3 Partnership Development

This project will establish formal lines of communication with national organizations with whom we have or desire to partner with on select projects or activities in line with our mission. The scope of work includes:

- #MEAction: Sustain an informal, cooperative relationship that maintains our independence. Many of our members are active with both organizations, and we can continue to work with #MEAction on public-facing events, such as collaborating on the annual #MillionsMissing event.
- Open Medicine Foundation (OMF): Holding focused dialog with Linda Tennenbaum regarding what role the Association can play in supporting the Harvard/MGH Collaborative ME/CFS Research Center or other initiatives related to clinical care in Massachusetts
- Solve ME/CFS Initiative (SMCI): Participating in national advocacy and public



awareness campaigns led by SMCI, and availing the Association of the technical support and guidance offered by SMCI through their developing partner program

4.4 Fill Leadership Positions

This project will fill the leadership roles of the Association. Because a decision remains to be made on paid staff, this project includes board and volunteer positions only. The scope of work includes:

- Create a pipeline for board membership
- Recruit volunteers to head committees with no current leader:

4.5 Paid Staff Analysis

While the Association has the financial resources to hire a Head of Operations and/or an Administrative Assistant for at least one year, consensus does not exist that it is prudent to do so at this time. This project will establish a business case to assist the board in reaching a hiring decision. The scope of work includes:

- Establishing job description for the Association's head of operations and Administrative Assistant
- Establishing salary ranges for both positions
- Determining the legal and human resource management responsibilities the Association would take on (what is required and what is optional but desirable)
- Estimate increases in annual revenues from all sources (donations, grants, services) that can reasonably be expected given the involvement of paid staff
- Compare the likelihood of the Association achieving strategic plan outcomes with versus without paid staff

4.6 Fundraising Program

This project will create a fundraising program to fully fund operations in accordance with the strategic plan. This project is dependent upon completion of Project 4.5 (Paid Staff Analysis) since the determination of whether to hire staff will have the greatest bearing on funding requirements. The Rare Genes Alliance in Rare Diseases publishes toolkits and guidance for developing fundraising programs applicable to the Association. An array of options are available, including the support and guidance to develop a program, all of which is described [here](#). The scope of work for this project includes:

- Building the case for donating to the ME/CFS and FM Association, Inc. (most of this can be taken from this strategic plan)
- Reviewing donation history, categorizing donors, their motivations and capacities to give
- Developing an outreach strategy that includes, at a minimum:
 - Clear messaging and "asks" targeted to donor categories
 - Grant identification and application writing
- Setting expectations for board member participation in fundraising
- Setting fundraising goals and a monitoring process



4.7 Membership Drive

This project will clarify what it means to be a member, make it easy to do and create an outreach campaign to attract new members to the Association.

4.8 Collaboration With Other Chronic Illness Organizations

This project would establish contacts at local organizations devoted to people with various chronic illnesses and disabilities. Through these contacts, we will look for opportunities to collaborate on events, public awareness initiatives, fundraisers, and political advocacy. Establishing connections and collaborations with organizations focused on other diseases and disabilities will allow our organization to access a wider network of service providers, patients and caretakers, and potential donors, and will emphasize our commitment to advancing education and funding for the benefit of the entire community of those with chronic illnesses and disabilities.

4.2 Priorities

It is neither feasible, nor advisable for the Association to undertake all projects at once. Several projects have dependencies, which dictate the ordering. But more importantly, the projects do not all deserve the same level of attention. While the projects do, as a whole, represent what is necessary and sufficient to meet the mission, we must focus initially on projects which can be accomplished with our current human resources and funds. Over time, we can initiate other projects as priorities evolve and resources allow. We established priorities based upon two independent measures: 1) Importance; and (2) Practicality.

4.2.1 Importance

To measure importance, we determined the degree to which each project might advance each of the seven goals. Importance scores were established by scoring each project against each goal and summing the results. We utilized an on-line voting tool for this process. The tool can be viewed [here](#). An analysis of the voting outcomes may be viewed [here](#).

4.2.2 Practicality

We considered the practicality of doing the projects based upon:

- Availability of volunteers to do the work
- Availability of a Project Manager to lead the work
- Cost of the projects
- Length of time to complete the project

This process was done by discussion and group agreement.

4.2.3 Executing the Work

After analyzing the practicality of our most important projects, we grouped all projects into one of three categories:

- **Must Do/Can Do Now.** These projects have the highest level of importance and can be undertaken with our existing volunteers and financial resources.



- **Must Do/Can't Do Yet.** These projects have the highest level of importance but cannot be undertaken until other projects or activities are completed.
- **Do as Time Permits.** These projects should be undertaken as time permits. Some of these projects are on-going and should be accelerated if and when possible. Others are of lesser priority and can be undertaken if and when resources are available.

The results of the prioritization process are summarized in Table 2.

Table 2: Projects by Priority

MUST DO/CAN DO NOW
1.1. Doctor Database Update
2.1. Revitalize MAC
4.2. Communications plan
1.2. Small Group Connection Program
2.2. Design Education Program for PCPs
1.4. Doctor Referral Feedback
4.1. Volunteer Recruitment, Education and Recognition Program
MUST DO/CAN'T DO NOW
1.6. Website Improvements - depends upon the outcome of Project 4.2
2.3. Conduct Training Sessions for PCPs - depends upon the outcome of Project 2.2
4.6. Fundraising Program - requires information from "must do/can do" projects
4.7. Membership Drive - requires information from "must do/can do" projects
3.3. Develop Program with Other Social Service Agencies - resource limitations
4.3. Partnership Development - resource limitations
2.4. ME/CFS Clinical Center - requires completion of Project 2.1
4.5. Paid Staff Analysis - requires information from "must do/can do" projects
DO AS RESOURCES ALLOW
1.5. Handling Complex Support Group Requests
3.1. Expand Program with MRC - this project is ongoing
3.4. Advocacy Coordination - this project is ongoing
3.5 Social Services Member Survey
4.4. Fill Leadership Positions - this project is ongoing
1.3. Support Group Program
3.2. Conduct Study on ME/CFS Patient Support Needs
4.8 Collaboration with Other Chronic Illness Organizations
2.5. Student internship



5.0 Next Steps

A plan is only as good as its implementation. While considerable effort has gone into creating this strategic plan, the real work – making it happen – lies ahead.

1. A final draft of the plan must be formally approved by the Board of Directors.
2. The final draft must be presented to key volunteers and the larger membership. A decision must be made by the Board as to what portions of the plan will be presented, the type of feedback to be solicited and the changes the Board will consider making to the plan based upon that feedback. A template for presenting the plan to the membership may be found [here](#).
3. Project assignments must be made by the President of the Association. Each project must have a single Project Manager (PM). The PM must develop a project plan, with realistic deadlines and labor requirements. The PM should work with the Volunteer Coordinator to solicit volunteers as may be desirable or required for each project.
4. The President (or future paid Head of Operations) should establish a means of monitoring the progress being made on each project and reporting regularly to the Board.
5. The Executive Committee should establish a set of Key Performance Indicators (KPIs) and set out a clear plan for revisiting and checking KPIs against this plan annually.



APPENDICES

Strategic Plan Pre-work

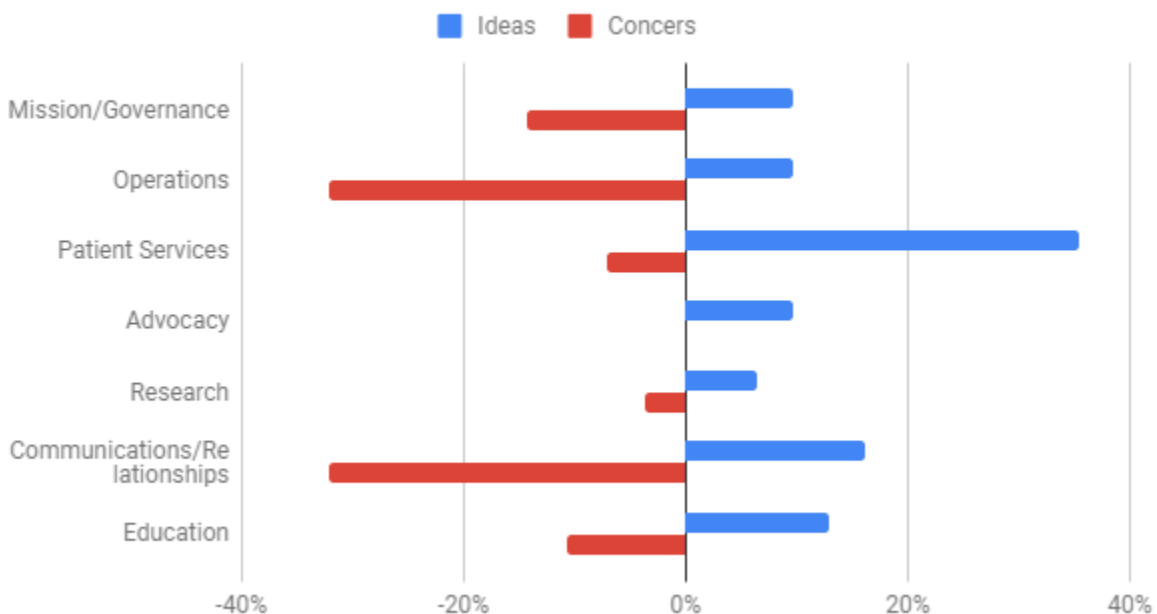
Prior to or facilitated work sessions, plan participants completed an on-line survey in which they were asked to identify up to five **ideas** and five **concerns**. They also noted what they hoped to do, personally, in the coming years in support of whatever strategic direction came out of the planning process.

The ideas represent what participants envisioned as realistic (and exciting) improvements or advancements the Association might embrace. Many of them helped to define our pillars. Some of them were acknowledged as outside our newly defined mission. Most of the ideas related to improvements in patient services and communications. The full list of ideas may be found here > [Ideas Sheet](#)

The concerns represent what participants worry about. Most of these related to operational matters and communications and, indeed generally reflect the concerns that led us to implement the strategic planning process in the first place. The full list of concerns may be found here > [Concerns Sheet](#)

The chart below illustrates the relative number of ideas and concerns, by category.

Ideas and Concerns - percent of responses by category





This is a biggie and we must deal with it, but there is a lot of Association history that must be reviewed and understood in order for us to do justice to this discussion and to make an informed decision about it.

Other, minor comments/concerns include:

- Let's come up with a single word to express each pillar
- The mission statement is a bit wordy. Maybe we should try to shorten it or, if we can't come up with a good way to do that, let's come up with a tag-line (maybe the words for each pillar or something of this sort).

Detailed comments received on the outline may be found [here](#).

Suggestions regarding the role of the Medical Advisory Committee may be found [here](#).

A first draft was produced on September 4, 2018 and reviewed by participants, some of whom used Google doc's on-line comment tool where the comments and responses are preserved. Others provided written comments, which may be found [here](#).

Three first draft review meetings were held to discuss review comments and produce a final draft. Notes from the meetings may be found [here](#).