

Four months have passed since my last letter. Much has happened since the launch of our revised website last March. In this letter I want to report on some of the activities and plans close to home.

On Membership

Our Board has formed a new Membership Committee to revitalize the Association membership. For many years, since its inception, our all volunteer organization had a large membership which enabled the Association to publish The Update newsletter, sponsor periodic lectures, and maintain the key services we were and still are providing such as the Information (Help) line, physician referral, and support groups. Now that the new website has launched, enabling new means of handling data, we are turning our attention to rebuilding our membership.

A larger and active membership will allow us to address some key goals, such as:

- closer contact with CFS/ME and FM patients and their families;
- more effective and informed communication with pertinent state and federal agencies and the legislature;
- hopefully easier recruitment of volunteers and Board members;
- enhancing our list of CFS knowledgeable health professionals;
- returning to sponsorship of periodic lectures;
- and re-establishing a stream of funding to at least partially support our services.

How many potential new members are there in Massachusetts? By conservative epidemiological estimates (using the prevalence rates found by Dr. L. Jason) there may well be over 27,000 CFS/ME patients in Massachusetts with two to four times that number of fibromyalgia patients!

The Membership Committee has just presented their revised recommendations and the Board will review them on August 1st. We plan to begin our new member recruitment in the early fall. In about two months we will announce the launch date. Please stay tuned.

On the Crucial Need for Volunteers

In order to continue those services that we have provided for many years as well as to add to those services and activities, we very much need additional volunteers. In order to recruit, train, and retain volunteers we have formed a Volunteers Committee. The range of needs is quite broad, from those requiring few skills and quite limited time to those requiring more specific knowledge and skills.

We have found that we need a mix of patients familiar with the illnesses (CFS/ME and FM) as well as healthy individuals. Our recruiting aims are directed to both. Please don't wait for us to contact you. Simply [contact us](#) to let us know of your interest and one of our Volunteers Committee members will be in touch with you. We will provide some basic training (no, not climbing over walls or other obstacles) as well as more specialized training when necessary.

Other Future Plans

Here is a sampling of some future goals that additional members and volunteers could make possible:

- Establishing a public information group to reach out to various forms of media. There is woeful ignorance and misinformation in the wider community about both CFS/ME and FM.
- Forming a small group of advocates to get familiar with the state legislature and legislators, as well as crucial government departments (health, education, justice). In our contacts with other CFS/ME and FM groups, for example in Vermont, New Jersey, and Connecticut, these connections have been vital to providing better education to key leaders as well as health professionals
- Our most difficult task over the years has been to refer patients to knowledgeable physicians. There is still a serious lack of the latter. Making stronger and more effective connections with health professionals such as physicians, nurses (especially school and public health nurses), psychologists (including school psychologists), and dentists, needs to be a priority. We have initiated contact with the state medical society but there is much more to do. Another sign of the need is that in none of the four medical schools in this state is there significant teaching about CFS, and the teaching about FM is very spotty. We are forming a Health Professionals Committee help plan the most effective ways of proceeding.
- While enlarging the membership will help provide additional funds, these will not at all be sufficient to maintain the educational and individual services of the Association. Like other similar organizations we will not only need to increase donations but also to seek grants for specific projects. We will need a cadre of volunteers to help us with fund raising and writing grant applications.

In the meantime please look at the new article in the website describing those services we are currently providing. Some of our Board members have suggested that we need to better inform our readers about all that we currently do.

In the next letter I will look at some of the news at a national and international level.

Alan Gurwitt
President, Mass. CFS/ME and FM Association