

There was (and is) much going on at Massachusetts CFIDS/ME & FM Association and elsewhere in both ME/CFS and FM communities. I was originally planning to report on many of the happenings but there is much information about them available elsewhere including on this website, so, instead, I will limit my reporting and remarks.

The BIG news at MassCFIDS this past autumn was the fact that we were one of the three ME/CFS organizations to win \$25,000 in the Chase Community Giving Contest, focused this year on relatively small charities. The very fact that ME/CFS organizations were among the winners in a national contest is big news in itself. Perhaps it is a sign of the increased self confidence and assertiveness in ME/CFS communities and organizations but also a function the number of advocates tuned in to the importance and needs of such groups.

Although there are many needs here in Massachusetts our Board has agreed to review carefully which of those needs, if met, would most benefit the most patients over time. We therefore are not rushing to make decisions but are aware that we must not dawdle. Our first full Board review takes place in early February.

At regional, national, and international levels there have been many unfolding events. Two of us attended the IACFS/ME Conference in Ottawa which not only featured many excellent presentations for patients and researchers and clinicians but, as usual, facilitated important informal connections between people from many countries. Similar connections also occurred at the excellent New Jersey CFS Association conference in October, thanks to the hospitality of their leaders. We were not able to attend the conference at the Mt. Sinai Medical School later in the fall but the fact that Dr. Derek Enlander has assembled an excellent group of researchers with backing from a major donor continues the trend started by the WPI, that is, private funding for ME/CFS research. Yet another even larger donation was made in New York with a new foundation being set up. While the involvement of private supporters is welcome, my hope is that there will be, in the future, a combination of government and private funding.

In early November our Association held a brief business meeting for the election of Board members followed by a report on the nature of the events of the IACFS/ME September Ottawa conference as well as an audio recording of Dr. Anthony Komaroff's selection of highlights of the conference. Dr. Kenneth Friedman, Board Member of the IACFS/ME and science advisor to many organizations, and I described the gist of some of the presentations and outlined the contents of the healthcare professional's primer on ME/CFS that will soon be released by the IACFS/ME. (See the summaries of the meeting. [Part 1 - Dr. Komaroff](#) , [Part 2 - Drs. Friedman and Gurwitt](#) .)

As regards government activities in this country the CFSAC meeting in November was full of information. Both the NIH and the CDC seem more involved although some of the news was

worrisome or at least unclear. A big question before and after the conference was: what changes to inaccurate information on their website would be made by the CDC and when would those changes be made? Furthermore, what is NIH's commitment to ME/CFS in the future? Clearly, continued active advocacy will be needed in the future.

To the credit of the CDC and Dr. Beth Unger, the CDC is reaching out to many state and other ME/CFS organizations with 2 hour conference calls with the goal of sharing information and becoming familiar with each other. This is a big advance over the past isolated and insulated stance on the part of the CDC. Our conference call with them was in November. It was generally cordial and quite informative although there were areas of disagreement and/or uncertainty. We have discussed our experience with other patient-serving organizations in two other states who have not yet talked with the CDC. Dr. Unger and her associate Dana Brimmer promised that after all the interviews were complete they would report on their impressions.

It is clear, from comments made by Dr. Unger and from a spate of recent emails written by ME/CFS advocates, that patient-connected organizations need to work closely together. How to best accomplish that along with clarifying the goals of a more widespread group is not a question for the future, it is an issue that should be tackled this year. This is not a new idea but the question is how can such a goal be achieved. There have been and still are efforts in that direction. The most recent have been the activities of P.A.N.D.O.R.A. and the Coalition4ME/CFS which have been pace setters in many ways including making it clear to the CDC what changes are necessary in its functioning, goals, and information provided to the public. It was their letter to the CDC, signed on to by other organizations, including ours, that paved the way for the CDC's reaching out.

Meanwhile, back to our home state, Massachusetts ME/CFS & FM Association needs volunteers, ill or healthy, who are willing to pitch in a couple of hours a week or more time if feasible. Most volunteer work is done at home with no need to travel. There are all kinds of skills needed. We will train you and be in regular contact with you by means of our newly augmented Volunteer Committee. Simply let us know of your interest via the Contact Us provision on this website or call our Info Line at 617.471.5559.

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