

Dear Members and Friends of Massachusetts CFIDS/ME & FM Association,

This is a special letter to tell you about the Association's recent work in advocacy, and **alert you to a very time-sensitive action** you can take.

Although the Association has always participated in advocacy, in the last few months our engagement has increased considerably, thanks primarily to the work of one of our Board members. In addition, Dr. Alan Gurwitt, past president of the Association who now organizing our Medical Advisory Committee, and I had the opportunity to represent the Association at the Fall 2012 meeting of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) in Washington, D.C. [Read our individual reports on the CFSAC meeting for our personal views and impressions, and get links to videos of the meeting](#)

Advocacy Alert – You can help! Deadline Nov. 1

Under a new law Prescription Drug User Fee Act (PDUFA V), the Food and Drug Administration (FDA) will be conducting an initiative, called the patient-focused drug development initiative, to provide for a more systematic approach to obtain the patient's perspective on the severity and currently available treatments for selected disease conditions. The intent is to ensure a thorough understanding of the severity of the treated condition and the adequacy of the existing treatment options.

This initiative will be conducted for each of 20 different disease areas over a period of 5 years. The FDA has nominated an initial list of 39 diseases, including ME/CFS and Fibromyalgia (FM). At a meeting next week on October 25, the FDA will narrow down this list of 39 to 20. Patient input is needed to ensure that ME/CFS and FM do not drop off the list!

The FDA will consider public comments received up to November 1st. We need patients to write letters describing the impact of these illnesses on their lives, as well as the (in)adequacy of current treatments. [Learn more and see a sample letter](#) (for ME/CFS) along with a chart of the illness severity characteristics the FDA will be evaluating.

New – National Advocacy Alliance for ME/CFS. This is a group of advocates from across the country who have gotten together in the last few months to organize a number of advocacy initiatives at the national level and projects on behalf of ME/CFS patients. Individuals, as well as patient associations and organizations, may “sign on” in support of each initiative. Our Association has recently signed on in support of several initiatives, in addition to taking one independent action. These are listed below with links to our website pages explaining more about each initiative.

- FDA: Requesting a meeting with Dr. Janet Woodcock [Joint Request from the ME/CFS Community for Action - Positive Response from the FDA](#). This is a request for the FDA to "fast-track" drugs for the treatment of ME/CFS. As a result of this letter, the FDA held a stakeholder meeting on Sept. 13, 2012, and there will be a follow up meeting early next year.
- [Health & Human Services: Request for meeting with Dr. Koh](#). A group of patient representatives requested to meet with Dr. Koh asking to work together with HHS to formulate a strategic, coordinated and fully funded response to ME/CFS. A follow up meeting was held in October with Dr. Nancy Lee, Designated Federal Official for the Chronic Fatigue Syndrome Advisory Committee, but the patient representatives are still asking to meet directly with Dr. Koh.
- [Centers for Disease Control and Prevention \(CDC\): Position Paper on CFS Toolkit and IACFS/ME Primer](#). This statement supports the June 2012 recommendation of CFSAC to remove the CFS Toolkit from the CDC website and make the IACFS/ME Primer widely available. The goal is to improve patient care by significantly improving the clinical guidance material available to medical providers, insurance companies, health clinics, secondary medical educators and patients.
- [American Psychiatric Association: National advocacy efforts state concerns about revisions to DSM-V](#). Members of our Association express concern about the inclusion of a code in the diagnostic manual for Somatic Symptom Disorder, which might allow psychiatrists to describe patients with ME/CFS as having a mental (rather than a medical) illness.

Alliance “Poster project” underway. Another initiative of the Alliance is to create a poster to spread awareness of ME/CFS. This poster design will be provided to local patient organizations, and has space for each to add its own name and contact information before printing the poster for its own use.

CDC Outreach. Finally, our Association was one of a number of patient organizations that were contacted directly by Dr. Elizabeth Unger, Chief of Chronic Viral Diseases branch and responsible for CFS at the Centers for Disease Control and Prevention (CDC). Dr. Unger has reached out to as many groups as possible over the last year for conversations so that she can

hear patient concerns and priorities directly from the groups who represent them. Although these were informal, not "official" meetings (e.g. no minutes of these conversations were published by the CDC), Dr. Unger promised to send out a brief summary of what she had learned from all the meetings, which she did. Although the response was very general, our Association appreciated the opportunity to have a direct conversation with Dr. Unger to express our concerns and priorities. [See the summary Dr. Unger sent to our Association](#)

The Massachusetts CFIDS/ME & FM Association welcomes the opportunity to join with others in advocating for more awareness, better funding, and more focused attention from our taxpayer-funded federal agencies. Although progress can seem painfully slow, some progress is being made. When we join with others, our collective voice becomes stronger.

Become a member!

If you are not yet a member, please [consider becoming a member](#) ! Although we do request a donation at the time of membership, if you cannot afford even a small amount, you can still join. Larger donations from those who can afford a little more help keep the Association running for the benefit of all.

Special note: *Our annual Member Meeting will be held in conjunction with the lecture by Dr. Byron Hyde, on Saturday, October 27. At that time we will present a brief update about the Association's activities in the past year, and present the slate of candidates for election to the Board.* Although pre-registration is closed for this event, walk-ins are welcome. We hope to see you there.

With warm regards,

Charmian Proskauer, President
Massachusetts CFIDS/ME & FM Association