President's Letter - September 2012

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

We have had a very busy and successful summer! At our Board meeting in June we reviewed our long list of mission-related activities and set our priorities for spending our grant from Chase Community Giving. That was a fun Board meeting! It is not often that we have been able to let our thinking stray far from "income" when thinking about doing something new that might cost money. After a good discussion, we all voted for our top priorities (no limit to the number of votes we each could cast) and there were 4 clear winners:

- Outreach to physicians and other health care professionals
- Outreach to youth, families and schools
- Public awareness
- Increasing our fund-raising to fully fund our operating budget

I am happy to report that we are already making significant progress on two of the goals, and are about to begin serious work on a third.

Conferences for School Nurses
For some time, we have been wanting to do something specific for youth, families and schools. We decided that a good audience would be school nurses, since all children have to go to school, even children who may be very ill, and school nurses would be likely to have contact with these ill children.

In August, we had the opportunity to make a 60-minute presentation to 175 school nurses at the Northeastern University School Health Institute annual conference. We also had two exhibit tables at this same conference. We have been working on this since last November, and it was a big success. We had 3 of our members tell their personal stories – two who have had CFIDS/ME/CFS since age 16, and one parent who has three children with the illness. These stories were very moving, and the audience of school nurses was riveted. We followed this with a brief review of the medical aspects of pediatric CFIDS/ME/CFS presented by Dr. Alan Gurwitt, board member and chair of our Medical Advisory Committee, who saw nearly 100 pediatric patients/families with the illness before he retired from active practice. At the beginning of the presentation, we asked how many in the audience had or thought they might have seen students with this illness, and about 10% tentatively raised their hands. At the end, when we asked the same question, at least 1/3 of hands shot up.

We had prepared a Resource CD with much written information about this illness in children as well as some standard reference material: diagnostic criteria, helpful articles for families and youth, basic and recent medical research, resources to help families navigate the educational system on behalf of their ill children, and a special "quick reference" section for school nurses. We gave a copy of this Resource CD to each attendee and had extras available at the exhibit tables. We spoke in person with a number of school nurses who have ill students in their schools, gave out 270 copies of the CD (many took an extra for a family or school guidance counselor/administrator or nursing supervisor), and over 40 nurses signed up for more information. We plan to create a special newsletter series for school nurses.

At this conference we received an invitation to exhibit at another school nurse conference the following week, this one sponsored by Children's Hospital Boston (CHB). We gave out the Resource CD to most of the 125 attendees along with a printed Resource List and our Association brochure, and acquired more names for our school nurses mailing list. At this conference we were invited to present at CHB's evening series of continuing education sessions for school nurses, which we will do this coming winter!

As part of the preparation for these conferences, we completely re-did our exhibit materials (posters, handouts) and now are ready to respond to other invitations to exhibit. We feel that educating school nurses will be a big step forward in reaching out to and supporting youth with CFIDS/ME/CFS and their families. A future step is to form a support network for youth and families. A big thank-you to the many volunteers who helped with these projects!

Book Talk
We held a smaller event in Sturbridge, MA, in early August. Novelist Roger King, author of Love and Fatigue in America, read from his book describing his personal experience with ME and the American health care system (compared with the British National Health Service). It is a serious look at the illness but told with grace and humor. We all enjoyed talking with him, and it was an opportunity to meet Association members and friends who have difficulty travelling to Boston for our regular lectures. We hope to do more informal events in other parts of the state in the future. If you have an idea for a local event and could help organize it, please Contact Us.

Fall Lecture and Member Meeting
Speaking of lectures, our fall lecture will be given on October 27, 2012, by Dr. Byron Hyde of the Nightingale Research Foundation in Ottawa, CA . Save the date! Dr. Hyde is writing a new book, tentatively titled Why Doctors Can't Diagnose, and that will be his topic. We will be making a video of his talk available on our website after the lecture, but it will be a treat to meet this internationally-known clinician and researcher in person.

Our annual Member Meeting will also take place on October 27. Before the lecture begins, there will be a short update on the Association's activities followed by election of the slate of Board members. This is an opportunity to "meet and greet" Board members and other volunteers, and find out how you might be able to help!

Medical Advisory Committee
Our Medical Advisory Committee is getting organized under Dr. Alan Gurwitt's leadership. This group will help us find ways to reach out to physicians and other health care professionals, and in particular, help publicize and distribute the IACFS/ME's Primer for Clinical Practitioners within Massachusetts. We are working with the IACFS/ME (International Association for CFS/ME) to find a way to allow both patients and professionals to obtain a professionally printed copy at low or no cost. Dr. Gurwitt is also working under the auspices of the IACFS/ME with some other members of the original authoring group to make some revisions to the text which have been suggested by both clinicians and patients.

Recognizing our volunteers!
All active volunteers (over 40!) were invited to our informal Summer Board Meeting. It was an opportunity for meeting and socializing with, and formally recognizing and thanking those who keep our Association running, providing needed services to patients and families, and working on new projects and initiatives. We were graciously (and deliciously) hosted by one of our board members, who also gave each person who attended a thank-you gift! This was a wonderful afternoon, only slightly impacted by cloudy skies and sprinkles.

Volunteer opportunities
We are starting a project to improve our website to make the content easier to find. We are in need of more volunteers to work on the website – writing articles and new items, updating content, and helping to implement changes. Our system is easy to use, but some training would be required. You would be joining a group of experienced folks who can help you learn and gain confidence. We do most of the work from home and via conference call, but some in person meetings might also be needed. We are also in need of more volunteers for our Information Line. If you are a patient yourself, have a couple of hours a twice a month, and would enjoy speaking with other patients on the phone, please consider helping in this way. If either of these opportunities interests you, please Contact Us.

Fund-raising
Finally, we are beginning to think seriously about fund-raising. As an all-volunteer organization with no paid staff and no office, our expenses are modest, but membership donations, as important as they are, cover only 25% of our expenses. Our Board is beginning to get better educated about fund-raising and looking forward to finding ways to put our Association in a sustainable financial situation. If you have expertise in this area and could help or advise, we would like to hear from you!

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.

In my next letter I will address the topics of Research and Advocacy.

With warm regards,

Charmian Proskauer, President
Massachusetts CFIDS/ME & FM Association