



This letter is mostly focused on our Association as there have been, over the past eight months, many changes planned and gradually implemented. While we have continued our full range of programs and services, we have become aware that planning for the future also requires time and attention.

One change is that this will be my last letter as president of the Massachusetts CFIDS/ME & FM Association. I have served in that role for four years and will be stepping down as president at the end of May to take on a different long term goal for our Association, namely, the establishment of a Medical Advisory and Physician Outreach Committee. I will continue to serve on the Board.

Such a move is possible as a result of active and successful recruiting efforts. We now have many capable new Board members and volunteers who can step into key positions. At our most recent Board meeting several leadership decisions were made. Charmian Proskauer was elected to become our new president starting in June. Charmian has served in many essential roles over the past few years and is very familiar with all aspects of our organization. We have other experienced volunteers serving as officers and as coordinators in our four newly created program areas: Education, Outreach & Advocacy; Patient Services; Communications; and Association Support. We also have many new volunteers working with committees and on individual projects. Welcome to all!

We have added two components to our recruiting efforts, namely, beefed up training of volunteers along with assigned mentoring by senior members. We also recognized that our previous governance structure, good for times past, needed some changes so that the president is not overwhelmed with responsibilities that can and should be spread out. The changes allow leadership to be more widely shared and supported by a better internal communication system.

We have rediscovered that growth, change and transitions are challenging. However we are aware that if we are going to be able to recruit more knowledgeable healthcare providers (a

crucial step), focus more on children and their parents, educate school nurses, reach out to more ill people, establish working relationships with legislators, etc. we must gear up to meet those challenges. We continue to need new volunteers, so if you are interested in contributing to this work, please let us know.

Since we heard the good news about receiving the Chase Community Giving grant of \$25,000, our Board members have been thinking about and discussing the best uses of those funds. While the proposed ideas cover a wide range of activities, it is no surprise that there is so much agreement about key priorities, which include: increasing public awareness and public education, improving physician education and outreach, and doing more to help children and their families. At the same time, we need to get much better at raising the funds we need to do this work so that the Association can continue to be a strong presence into the future.

It has been my good fortune to serve on the IACFS/ME Primer Committee. Except for one last review the Primer is about done. It has taken almost two years but there was no way to shorten the process. The IACFS/ME plans to circulate the Primer worldwide in two forms, one via the internet so it can be downloaded free, and for those who prefer, in printed form at a nominal cost. We on the Primer Committee hope very much that it will prove useful in educating healthcare providers which is urgently needed. We also hope it will be helpful to patients.

I have been very fortunate to have served as president of the Massachusetts CFIDS/ME & FM Association and want to publicly thank everyone connected to this wonderful group. I also want to thank you, our members and friends, for bearing with me and for sending me your thoughts and suggestions. The worlds of ME/CFS and Fibromyalgia have changed over the past four years and I am optimistic that better times, better knowledge, and better help are ahead.

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