

June, 2012

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

This is an exciting and hopeful time for ME/CFS patients.

- There is a continuing flow of promising research in many areas, including a major federally-funded effort to collect data and biological samples from patients which may be used in future studies. This new approach will allow researchers to study separately “sub-groups” of patients who have similar characteristics, rather than basing research on large heterogeneous groups, which may obscure real results.

- Private money is funding several significant new research initiatives.

- The CDC and NIH seem to be making slow but definite progress in “getting it” about this illness, and responding with better information for health care providers and the public.

- The CFS Advisory Committee, the primary federal-level cross-agency group focused on ME/CFS, devoted most of one day of the spring meeting to ME/CFS in children and adolescents, with both formal presentations and a panel discussion. There was a session on ME/CFS organizations (e.g. state and regional patient associations and advocacy groups) on the second day. We are finally being heard!

- The critical “symptom” of “Post Exercise Malaise” (that familiar crash after doing too much) is becoming understood as a defining characteristic of the illness, a biological reality that easily differentiates ME/CFS from depression and other fatiguing illnesses, and in kids, from school phobia. The amount of exercise that is safe for an individual patient can now be scientifically measured. Although this testing is expensive and limited to a few labs in the U.S., it provides an absolute refutation of the one-size-fits-all approach promoted by the dreaded G.E.T. (Graded Exercise Therapy) protocol.

Here in Massachusetts, our Association is expanding outreach and beginning to connect with more patients. “Virtual” communication, such as our website, e-newsletter, videotaped lectures, and webinars make it possible for even home-bound patients to stay connected, as long as they have a computer and are online, as more and more are. We are also responding to renewed interest from patients in getting together in person, through our lecture series, some smaller events around the state, and support groups. A new support group in Central MA is attracting people from a wide area including northern Connecticut. We continue to provide an Information Line where callers can speak by phone with our volunteers, physician referral (Massachusetts only), and disability information and counseling. Our website, www.masscfids.org, is an excellent source of basic and more detailed information about these illnesses, as well as

disability information. Weekly postings bring together News from Around the Web, and links on the home page highlight new and original content.

Our lecture series for 2012 features two major speakers: Dr. Benjamin Natelson spoke this spring, and we will have Dr. Byron Hyde in the fall. We are also presenting a one-hour session this summer at the Northeastern University School Health Institute conference (for 300+ school nurses from all over Massachusetts), "Recognizing and Managing Children and Adolescents with Chronic Fatigue Syndrome in a School Setting," at which three of our members will be telling their own stories of having ME/CFS as children or being parents of children with the illness. We are also planning programs which focus on Fibromyalgia.

We continue to build relationships with other state and regional ME/CFS organizations in order to join together to speak with a stronger voice in advocacy. We were signers of a letter to the CFS Advisory Committee in advance of their spring meeting, and we have also filed public comment on proposed changes in DSM-5. You may see both of these letters on our website.

We were thrilled to have received a \$25,000 grant from Chase Community Giving this past winter, and are working very hard to ensure that these funds are used in ways that both address our mission of Education, Support and Advocacy, and also make our own Association stronger so that we can continue this work well into the future (wouldn't it be amazing if some day we will no longer be needed?). We have expanded our Board and have incorporated many new volunteers into both key and supporting roles. Finally, we have improved our governance structure to help our committees communicate better with one another and distribute leadership roles more evenly, and elected new officers so we can have fresh energy while retaining the wisdom of those who have already served.

In the coming year we will be focusing on public awareness, physician education, and ensuring financial stability and sustainability. About these topics you will surely hear more in the future.

Our Association depends on YOU, as members, volunteers, and interested persons. If you are a patient with ME/CFS or Fibromyalgia, or a family member or friend, we want to hear from you.

What ideas do you have for events? Would you like to talk with other folks in a support group setting? Can you contribute some of your time to help with advocacy, planning or helping out at events, working on our website, talking with other patients? How can we all spread the word that ME/CFS is a "real" illness, and worthy of more research? You can send your comments via

[Contact Us](#)

on our website,
www.masscfids.org

If you are not receiving our electronic newsletter regularly, you may [sign up](#) . The newsletter is free and will help you stay up to date on important developments that affect you.

If you are not already a member of Massachusetts CFIDS/ME & FM Association, please consider becoming one and, if you can, making a donation to support this work. Even if you cannot afford to donate, you can still help by [becoming a member](#) . Becoming a member shows that you share a commitment to help everyone with these illnesses, through advocacy, education, and helping to provide direct services to patients. Every voice counts and your support makes a difference.

We do not have paid staff or maintain offices; all of us are volunteers and work from home. Every dollar goes to supporting our work. More information about [membership](#) , [volunteering](#) and [donating](#) can be found on our website, www.masscfids.org

In closing, let me say that I am both honored and humbled to be following in the steps of the former Association President, Dr. Alan Gurwitt. I could not have even considered trying if it were not for the wonderful support of our growing group of volunteers, Board members and advisors.

Charmian Proskauer, President
Massachusetts CFIDS/ME & FM Association