

[See the slides for this presentation](#) .

Thank you, Dr. Marshall and members of the Committee.

You have already received a one page description of our organization, the Massachusetts CFIDS/ME & FM Association.

I would like to highlight several aspects:

About Us

We are a frontline group, made up of all volunteers, most of whom are patients with either ME/CFS, fibromyalgia, or both. As far as we know we are the oldest such organization in the United States.

We published the first Primer for physicians and other healthcare providers 20 years ago, in 1992. It was distributed throughout Massachusetts but we received requests for it from all over the world as there was simply nothing else then available.

For many years we published *The Update*, an educational publication that was an important source of information for patients and families. It had a wide circulation going far beyond Massachusetts.

In addition we sponsored many lectures and other educational programs in the past, and after a hiatus resumed doing so in 2010.

Highlights

We work collaboratively with other regional patient organizations and advocacy groups, sharing

knowledge and experience. Much of what we now do is based on that sharing.

We have a comprehensive website that is updated frequently. Our *Disability Handbook* is used by many.

In 2010 we videotaped the first lecture of our new series, Dr. Anthony Komaroff's excellent review of the state of knowledge about ME/CFS, which made it clear the ME/CFS was a real medical illness, and made it available to the world via our website. It has been translated into 4 languages and has had a major impact in several countries.

Current Projects

One of the recommendations coming out of your June meeting was to ask HHS to partner with Committee members and the Department of Education to educate educators and school nurses on pediatric ME/CFS. We are already actively educating school nurses in Massachusetts. Our presentation in August to 175 school nurse leaders was a conference show-stopper, and we are still receiving follow up invitations to present this material or exhibit at conferences for school nurses. The CD which you have received was created for use at these conferences.

By 2010 we were getting feedback from patients indicating that many physicians were saying that they were more open to believing that ME/CFS was a medical illness but they didn't understand it nor did they know how to diagnose and treat it.

When we looked around at what information was available for health care providers, we found nothing sufficiently up to date, comprehensive, and accurate. This led to my participating for almost two years in the writing of the IACFS/ME Primer. I am now serving on the revisions subcommittee.

We hope the Primer will help. The state of knowledge has advanced considerably over the last 5-10 years but there is still a huge gap in knowledge of ME/CFS as a medical illness that can be diagnosed and treated.

Challenges

Every week, as a frontline organization, we see evidence of ignorance or active rejection of what is now known. Misdiagnoses and inappropriate recommendations are harmful to patients in many ways. To educate healthcare providers requires not only specific and comprehensive information, but also requires a willingness to learn. There need to be strong efforts made to overcome the biases and intransigence at all levels of the medical establishment.

This includes medical school deans, residency training directors, educational institutions for other healthcare providers, editors and editorial boards of key journals, and leaders in organized medicine.

For that to happen, I think that the NIH and especially the CDC need to present clear, unambiguous and correct information about ME/CFS which reflects the current state of knowledge, and then speak out strongly and with conviction about the importance of learning about and teaching what is known. Yes, we need more research and more money, but we have to address the persistence of misinformation, and the lack of will for accepting and learning about the new research throughout the medical and scientific establishment. There are, at this time, NO excuses for ignorance and skepticism.

Thank you.
Alan Gurwitt, M.D.

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