



Trying to catch up on events locally and nationally is not easy as there have been many. Here I will focus on only four.

In April, with co-sponsorship and hosting by the Massachusetts Department of Public Health and its head of infectious diseases Dr. Alfred Demaria, we had the privilege of hearing **Dr.**

David Bell

, well known ME/CFS pioneer, address an audience of over 100 attendees. There were two portions, the initial (and surprise) presentation of a twenty five-year follow up study of pediatric patients initially seen by Dr. Bell during a now famous cluster outbreak in the rural Lyndonville, New York area. This follow up study, conducted with an academic colleague from Cornell, was presented again in London on May 20 at the Invest in ME conference. The video of Dr. Bell's lecture to us on April 16th, "25 Year Follow-up in Chronic Fatigue Syndrome: Rising Incapacity," is now posted on our website.

We, and the audience, had expected Dr. Bell to comment on the status of recent XMRV research and the (then) recently concluded NIH State of Knowledge conference. In the Question and Answer portion of our conference Dr. Bell explained why he decided to instead present his follow up study. There were two reasons: first, that study was one of very few long-term follow up reviews, and second, in his view, XMRV research is so complex and controversial that those of us in the ME/CFS community need to wait for the academic scientists to sort it all out. Actually we were not entirely deprived of his perspective as you will see and hear in his cogent remarks at the beginning of the Q&A.

Dr. Bell is at his best in responding to questions from the audience. You will see why Dr. Bell is considered such an astute clinician when you view the Q&A portion.

The second event I want to focus on is one that you may have missed unless you were able to see the video of the second day of the NIH State Of Knowledge conference which took place in April. There was a relatively short but powerful **personal statement made by Kenneth Friedman, Ph.D.** , formerly an associate

professor of physiology at one of the state medical schools in New Jersey. Dr. Friedman is a consultant on ME/CFS to three organizations: the New Jersey CFIDS Association, the Vermont CFS/ME Association, and P.A.N.D.O.R.A. He is the father of a young adult with ME/CFS and for years has been an outstanding advocate and spokesman. He was a key editor and author for the publication of the New Jersey Consensus Manual. He is an officer in the IACFS/ME and is a member of the IACFS committee drafting a physician's primer (scheduled for release in September of this year). For all of his efforts Dr. Friedman should have been receiving kudos but the powers that be in medical academia in New Jersey decided instead to punish him for his dedication to ME/CFS, stripping him of his faculty position. In his 12 minute NIH presentation Dr. Friedman described what happened to him and why that event is pertinent nationally.

Why is this important? For at least 25 years THE major reason why key research on CFS was not done in almost all medical schools and centers in this nation was the ignorance, bias, and group-think wall against seeing ME/CFS as a real medical illness worthy of study. Dr. Friedman courageously decided to lift the veil of silence about that fact in order to expose the long-term suppression of research and interest. It has happened in Massachusetts as well. We know of physicians and research scientists who were either warned away from work on ME/CFS by their colleagues or were unable to attain funding for that work. However, we in Massachusetts have been so very fortunate that Dr. Anthony Komaroff has been a leader of research and clinical work in the area of CFS, and has now been joined by other colleagues. There are signs of change for the better in this state.

We all know that there is need for much more research in the fields of ME/CFS and fibromyalgia. You can help that become a reality by mentioning that need to your own physicians and other health care providers. ME/CFS and Fibromyalgia are not rare illnesses, with at least twenty five to thirty thousand patients having the former and quadruple that number with the latter, in Massachusetts.

The third topic I want to touch on is some **recent history of our Association along with thoughts about future efforts**. Four years ago our Board members, all long time volunteers, while continuing to provide many needed services, were few in number and exhausted by their efforts. They decided they could not continue without new volunteers, including new Board members. With great effort they, we, have slowly added to our numbers which has enabled the revamping of our website, increased services, resumption of educational lectures, and some relief for those who had labored so long. We now have a larger board (ours is a "working board") and more volunteers, but we are not yet at the point where we can fully take on new and necessary tasks. One of those tasks is establishing an effective fund-raising effort—membership dues and donations help but are not sufficient. We would also like to devise and implement much stronger patient outreach and advocacy programs. At our July Board meeting we intend to review the progress so far, discuss what can

be improved upon, and determine what our priorities should be over the next year or two. We always welcome new volunteers, so please consider joining with us in whatever way you feel you can contribute.

Finally, please note an important event to take place next fall: preceding the fall educational event there will be a business **meeting where we will discuss the state of the Association and future directions**. You will have a chance to meet current members of the Board of Directors, vote for Directors-At-Large, and voice your views about the future direction of the Association—your Association. Please come and participate.

Alan Gurwitt, President
Massachusetts CFIDS/ME & FM Association

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