

In the world of science

There are many recent pieces of interesting news in the world of medical science with a common theme: Whether or not the possible linkage of the XMRV retrovirus to CFS/ME is confirmed there is clearly an upsurge of scientific interest and research. Those who follow Co-Cure and other CFS/ME sites can see for themselves indications of this upsurge.

An important summary and overview is the lecture, sponsored by our Association, given by Dr. Anthony Komaroff, Professor of Medicine at Harvard Medical School and Editor-in-Chief of Harvard Health Publications. His address on April 24th before a packed room at the Milton (MA) Hospital was an excellent summary of advances made in the understanding of CFS/ME. **I am pleased to announce that the video of the lecture along with the Q&A portion has been posted on our website.**

This video is free but if you find the information useful, please consider [making a donation](#) to our Association to defray expenses for this and future videos.

It is also clear that other institutions are gearing up to study the XMRV retrovirus in relation to CFS. One such study will be carried out in Boston. Other sources of information can be seen in the webinars being provided by CFIDS Association of America. These webinars cover a wide range of research and appear monthly. What is so interesting is that the research is diverse in nature, delving into basic biological mechanisms yet possibly interconnected.

At still another Boston medical center there has been active research on the role of Vitamin D in possibly helping patients with fibromyalgia. We are hoping that one of our volunteers will be doing a bit of investigative medical journalism on this story.

Important Notice. Australia, Canada, and New Zealand have decided against allowing patients with CFS/ME to be blood donors. While they have not definitively concluded that CFS/ME is contagious, they have decided that there is sufficient reason for caution. Such a decision has not been made in the U.S.A. or the UK, although in the latter, ME organizations have advised against giving blood. We think this is wise. Until such time as it is definitively proven that XMRV is or is not a contagious agent it is probably best that CFS/ME patients not contribute blood.

Our next lecture

Dr. David Bell, a CFS pioneer and renowned pediatrician has agreed to come to Massachusetts in late October to talk about CFS/ME and fibromyalgia in children, adolescents and families. We are considering including others with him—a local pediatrician, school nurses, school psychologists—as a panel. As soon as we know the date and location as well as the names and affiliations of the panelists we will announce it here as well as by email. We hope to make a video of this conference as well.

A step towards the education of Health Professionals

It is clear in Massachusetts, and from what we hear in other states, that there are still many health professionals who know little about the diagnosis and treatment of CFS/ME. This is also true for other professionals in the field of education. In regards to the former, the IACFS/ME has established a special committee that is hard at work on a primer that will provide essential information about the history, diagnosis, and treatment of this illness for an international audience of health professionals. I am fortunate enough to be participating in this committee's work and am much encouraged by the breadth of knowledge and expertise of its members. The challenge is to make the primer long enough to contain basic necessary information but not so long as to turn off busy health professionals. There are, or soon will be, two other sources in greater depth. One is "the Purple Manual" published by a British ME organization, last revised in 2009. The very useful New Jersey Manual, now 9 years old, is also now being revised.

Some actions being considered by our Board

It is clear that to have any impact on governmental services for CFS/ME and fibromyalgia patients we must become more active both educationally and via advocacy. Those of you who are Massachusetts residents can help here. Do you know legislators, governmental administrators, school personnel, etc.? Would you be willing to let us know about possible contacts? Please [contact us](#) . We will treat that information confidentially. We have learned that personal familiarity does make a difference.

We are continuing to update our list of health providers to be able to provide names of informed or at least willing-to-learn physicians, physician assistants, nurse practitioners, psychologists, social workers, etc. Requests for referrals are the most frequent services asked of us. Here too, you can help others. Please [let us know](#) about professionals with whom you have had personal experience. Who was helpful, who was not. This information will be treated confidentially.

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