

The good news is that there is much news of interest to report. Unfortunately, I can only report some of it.

Research news

There seems to be an increase in the number of international conferences about both CFIDS/ME and fibromyalgia. These conferences represent an increase in the volume of research and sharing of the information gleaned from that research. The caliber of most of the research is high. Gone is the predominance of emphasis on psychological issues. Where the funds are coming from is a mystery for some of the work but for other portions it is clear that there is private organizational support.

There has been much attention paid to the XMRV retrovirus information published last October in Science and the efforts afterwards to replicate the findings. While those efforts have so far been unsuccessful they have been criticized as failing to make use of key methods from the original research so that they are not true replications. There have been rumors to the effect that a NIH scientist may have crucial information on all of this but until his research is published in a reliable medical or scientific journal it is simply all speculation. We will have to wait and see. We will report on it when we know the facts.

Dr. Komaroff's lecture of April 24, 2010 is posted

Also on the good news side: Since the Dr. Anthony Komaroff lecture was posted on this website in May the feedback has been very positive. If you haven't already seen and/or listened to it please do so. I can assure you that you will come away with an increased understanding of CFS/ME. If you tried to watch the posted lecture before but were unable to view and hear the entire lecture, as well as the question and answer portion, we have recently posted other versions that require less bandwidth, so that older computers can handle it.

Dr. Komaroff's lecture was written up by one of our senior Board members with help from a new volunteer. This was done to make it easier for those of you who prefer information in written form. Also included is some commentary. Two other senior members were also part of the editorial team. We are currently recruiting volunteers to work with the Editorial Committee who would be willing to act as reporters, track down information and then write it up. If you are at all interested please contact our Editorial Committee at: webmaster@masscfids.org.

Fall lecture

On the bad news side, we have heard from Dr. David Bell that he will not be able to provide the fall lecture. Depending on his health he may be able to visit us next spring. We have not yet pinned down an alternative program but we are receiving suggestions. If you have any specific ideas or suggestion for a topic you would like to learn more about or particular person you would like to hear from please write me at: president@masscfids.org. Please do so as soon as possible as time is limited.

Physician's guide to CFIDS/ME

One of the major problems that many of you are aware of is the lack of sufficient numbers of physicians and other health providers who are knowledgeable about the diagnosis and treatment of CFIDS/ME. We hear from people every week about this problem. The pervasive skepticism about the existence of a real biological illness has diminished, but what has not changed is the lack of solid understanding of what CFIDS/ME is, how to diagnose it and how to treat it. In his lecture in April, Dr. Anthony Komaroff clearly stated that with more than 5,000 publications (books, scientific papers in medical journals, etc.) there should no longer be any doubt about the existence of a medical illness unfortunately named Chronic Fatigue Syndrome. (The patient community and some researchers use the term CFIDS.) It is NOT a psychological phenomenon. A challenge all along, once beyond the wall of doubts, is to provide comprehensive and concise information about the nature, diagnosis, and treatment of CFIDS/ME.

There have been many guidelines or manuals for clinicians generated over the years by various groups. This Association published what may have been the first primer in 1992. The New Jersey Association published a Medical Primer in 2002. Others have been published in Australia, New Zealand and the UK. With two exceptions these manuals, while very informative, are too long for most busy clinicians. On the other hand a set of guidelines that is too short simply can not provide adequate information. The challenge is to strike the most useful balance. The IACFS/ME, in recognition of the need for an up-to-date, not too long and not too short primer or set of guidelines, has established a 16 member international committee that is hard at work (and I do mean hard) putting together just such a primer. It will take some months to finish it but it is in the pipeline. As a member of that committee I am buoyed by the breadth of clinical and basic scientific knowledge of the members, but it is indeed a challenge to weave together what everyone has contributed. When it is finished the IACFS/ME will probably distribute it online and in published form. We will keep you posted.

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