“Chronic Fatigue Syndrome: Is there a virus?” was a course presented as a live lecture on February 22, 2011 — part of the Demystifying Medicine 2011 series sponsored by the National Institutes of Health (NIH). According to the NIH, these courses are “designed to help bridge the gap between advances in biology and their application to major human diseases.” These programs include a wide variety of topics and are intended primarily for medical students, fellows, clinicians and healthcare professionals as well as those seeking academic credit. After the program has aired, the recorded videos are available for viewing at the NIH website.

This lecture, approximately 2 hours long, was created to help “demystify” recent research, share current thoughts and discuss future plans regarding a virus (more specifically, a retrovirus) and its association with CFS. The three key speakers were Drs. Shyh-Ching Lo, a scientist from the Food and Drug Administration (FDA) with a long history in mycoplasma research, Harvey Alter, a senior NIH investigator who is recognized for his work with hepatitis, and Fred Gill, Chief of Internal Medicine Consultation Services at the NIH Clinical Center.

Introduction by Dr. Alter:

Dr. Harvey Alter provided background information about research developments surrounding CFS, more specifically, studies over the last couple of years which have sparked a lot of interest and hope as well as much debate. The first part of his presentation starts at the 5 minute point, lasting for about 15 minutes, during which he goes over the initial XMRV discovery and subsequent studies — it is brief but informative. Dr. Alter speaks again at the end of this program and discusses a study that will take place in the near future (within next 6 months), which in his opinion, should settle the XMRV debate. (Dr. Alter's slides are available separate from the videocast at http://demystifyingmedicine.od.nih.gov/DM11/02-22-2011/2011-02-22-Alter.htm)

First speaker, Dr. Fred Gill:

Prior to Dr. Gill’s presentation, one of his patients spoke about her rapid onset and experience with CFS. Out of respect for a fellow person with CFIDS, we are not including any part of her testimony and applaud her courage and honesty.

Dr. Fred Gill began his part of this course by stating the thoughts and viewpoints he would be sharing represents the “party-line/ CDC, NIH” community. It sounded like one of those situations when someone tries to convince an audience that he “gets it” while saying how many others don’t or uphold even worse opinions. Having said so, a good deal of the information presented

by Dr. Gill was outdated, including his point that CFS is a “real illness.” Whether CFS is a real illness was severely questioned during the 1990s and early 2000s by the NIH and CDC. At this point the debate should be over - it is a real illness. In tracing the “supposed” history of CFS, he reverted back to the assumption that the “neurasthenia” of 1869 (termed by Dr. Beard) was an early form of CFS (i.e. a type of nervous exhaustion). Although this has been stated before, it seems only an inept speculation based on superficial symptoms which morphed over time into some vague psychiatric category. In his presentation of his case the patient’s history was sloppily told. The patient presented a straightforward account of her illness with many potential teaching aspects almost completely missed by Dr. Gill.

When discussing the diagnostic process, Dr. Gill stated that routine blood work such as a blood count, sedimentation rate, chemistry screen, and TSH levels are the only recommended tests. He stated that advanced studies (i.e., to check immune system, viral loads, or orthostatic hypotension), based on his own experience and findings by the CDC, were found not to be worthwhile and are not recommended. He further stated there has not been any proven association of CFS with earlier viruses (like Epstein Barr Virus and other HHV (human herpes viruses)) nor are there any documented differences in patients with CFS and healthy controls as far as orthostatic intolerance (OI) goes. Despite these symptoms being part of 1994 diagnostic criteria (which Dr. Gill favors), he specified that fever can only be acknowledged if/when it goes over 100.3F; lymph nodes might be painful, but rarely present as lymphadenopathy; and joints and muscles might also be painful, but they don’t limit motion. Dr. Gill described patients with CFS as being previously highly functioning individuals who come with subjective features of CFS which tend to fluctuate over time. His recommendations are Cognitive Behavioral Therapy (CBT) and graded exercise therapy (GET) as two of the most beneficial treatments for CFS and to support this, he cited the recent UK-published PACE study as objective proof that CBT and GET do work. In response to one of the questions during the Q&A session on epidemiology, Dr. Gill thought CFS is more dominant in affluent and educated societies, but said there were no solid studies.

It would be an understatement to say that the information presented about CFS by Dr. Gill for a significant portion of this course (about 45 minutes), was very deficient and much of it could be regarded as “disinformation,” especially given the targeted audience of medical students and providers.

Second speaker, Dr. Shyh-Ching Lo:

Dr. Lo’s presentation starts at the 65 minute point into this course and lasts for about 40 minutes. His material was highly technical and might be found too detailed by the average person to fully comprehend, but it definitely provided great insight about how XMRV / MLV tests were conducted and what might have led to the discrepancies in results of other studies.

Unfortunately, the videocast of this course did not show any of his slides and many of the captions contained errors in the words/terms used or they were completely omitted. However his slides can be viewed separately at http://demystifyingmedicine.od.nih.gov/DM11/02-22-2011/2011-02-22-Lo.htm .

Dr. Lo went over various testing techniques used in his study with Dr. Alter. An article about their study can be viewed on our website by clicking on the title, "NIH-FDA-Harvard Medical School study finds a "strong association" between CFS/CFIDS/ME and closely related retroviruses."

Dr. Lo reported their study found that the gag and env sequences from CFS patients were more closely related to polytropic mouse endogenous retroviruses than to those of XMRVs. He recommends the use of highly sensitive assays, like mitochondrial sequencing. He further pointed out that the CDC had used a mitochondrial sequencing technique different from the Lo/Alter study, which in Lo's opinion, affected the sensitivity of the test.

Other XMRV studies were reviewed and reasons were given for different results such as geographic region, patient groups, mixture of different disease in groups, variations in PCR protocols used, the kits used for testing and amplification of signals, preparation and processing of tests, and tissues that most likely were contaminated with mouse DNA. Dr. Lo repeatedly defended the Lo/Alter study results for their accuracy. They also detected differences in titers, which were found lower in patients who were in the 'wax and wane' stages. Lastly, Lo stated that disease association with test results is not yet known.

Conclusion by Dr. Harvey Alter and upcoming NIAID study to end XMRV debate:

Dr. Alter concluded the course by raising questions about etiology – is CFS linked to a virus/ viral agent? Did the diversity of sampling sites or potential contamination outside of the study sites (where specimens were drawn or something different about the patients themselves, like common treatments they had received) create the mixed results?

Dr. Alter reported on an upcoming study, sponsored by the National Institute of Allergy and Infectious Disease (NIAID) and headed by Dr. W. Ian Lipkin, which is designed to resolve the XMRV debate. This study will include a large population of "classic cases" of CFS, using the Canadian criteria (patients who had an acute onset). Samples will be sent to Dr Lipkin's offices

where they will be prepared and coded in triplicate. Panels will be developed and sent to those labs where patients were previously tested for XMRV. Each lab will use their own assays and submit their coded results. The codes will be broken at the coordinating center. The results will be published either way. If these tests are all negative, the conclusion will be that "the original findings will be considered unconfirmed." If, on the other hand, the results do show that the virus can be consistently detected in patient samples but not in controls, or in different ratios in patients vs. controls, then the original findings will be considered to have been confirmed. This data should be available within the next 6 months. If an association is confirmed, this does not establish causality. Further work will be required to look at that question.

The video recording of this program, " Chronic Fatigue Syndrome: Is There a Virus? ", can be viewed at the NIH videocast site.

For another view of this presentation, see the blog post by 20-year PWC Charlotte von Salis , who was (she stated) the only representative of the general public and the patient community to attend the session in person. Ms. von Salis spoke during the question and answer part of the program.