

Welcome to 2014!

We hope you survived the holidays and are starting out the New Year with hope and at least a glimmer of optimism. This promises to be a year of action and hopefully, some progress.

Video of Dr. Anthony Komaroff's 2013 Lecture is now available

Links to the video-recording of the Fall 2013 Lecture by Dr. Anthony Komaroff are now available on our home page. Dr. Komaroff discussed "CFS Research: Recent Progress and Challenges" and took many questions from the audience.

- Dr. Anthony Komaroff's 2013 lecture " [CFS Research: Recent Progress and Challenges](#) " (56 minutes)
- Dr. Komaroff's 2013 lecture [Questions & Answers](#) (37 minutes)

The video-recording of the Spring 2013 lecture, " [The Science of Sleep](#) ," presented by Dr. Jo Solet is also available.

Have you experienced more than your share of dental problems?

Dry mouth and various oral and dental complications are problematic for many people with Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalomyelitis (CFIDS/ME), and/or Fibromyalgia (FM). Persistent dryness could indicate an autoimmune illness like Sjögren's Syndrome, linked to poorly functioning or damaged salivary glands, or be the result of side effects from many medications. Either way, it is a serious problem that warrants prompt medical or dental attention.

This new article provides information about the serious and often devastating consequences of persistent dry mouth and treatments that can help to protect teeth and restore oral health. Read more at [Oral Complications in Sjögren's Syndrome and Chronic Dry Mouth](#) .

CFS/ME Research Updates – the search for biomarkers

" [Immune Abnormalities in Patients Meeting New Diagnostic Criteria for Chronic Fatigue](#)

[Syndrome/Myalgic Encephalomyelitis](#) " is a study conducted by Dr. Ekua W. Brenu and a group of researchers from Queensland, Australia, and is the first one to investigate whether immunological differences might be found among patients who met different diagnostic criteria for CFS/ME. Some of the patients fulfilled the criteria for the 1994 Centers for Disease Control and Prevention (CDC) while others fulfilled the 2011 International Consensus Criteria (ICC). Their study revealed more differences between the ICC diagnosed patient group and the controls than between the 1994 CDC cases and the controls. Moreover, significant differences were found in the expression of natural killer (NK) receptors in patients with moderate and severe symptoms. The research team concludes their approach might be useful in future evaluation and differentiation of patients into subgroups.

[Ed. note: NK cells are a type of lymphocyte (a white blood cell) and a component of a person's innate immune system.]

" [Deficient EBV-Specific B- and T-Cell Response in Patients with Chronic Fatigue Syndrome](#) " is a comprehensive study carried out by fifteen researchers at the Charité University Medicine Berlin, Germany. Their research concentrated on Epstein-Barr virus (EBV) reactivation and EBV-related impairments or abnormalities in CFS.

"For many years, researchers have suspected EBV to be involved in CFS... In a subset of patients the disease starts with infectious mononucleosis and both enhanced and diminished EBV-specific antibody titers have been reported.... A hallmark of CFS is chronic activation of the immune system, which can be triggered by infections or non-infectious agents. Although altered EBV-specific antibody titers have been repeatedly demonstrated in CFS, no clear evidence for chronic EBV replication has been obtained so far."

The authors provide such evidence, and suggest that the altered immune response to EBV may be a biomarker for the illness.

A summary of their findings and conclusions is listed below:

- "First of all we could confirm previous reports providing serological evidence of EBV reactivation ...
- "In line with this finding we could provide evidence of enhanced viral load of EBV by detection of EBV DNA in a significantly higher proportion of patients compared to healthy controls. However, no patient showed a high viral load as seen in EBV-associated post-transplant lymphoproliferative disorder or acute infectious mononucleosis. Further, we had no evidence of lytic replication...

- "Thus, our findings suggest a higher level of latency-associated replication in CFS patients.
- "Based on our findings we assume frequent EBV reactivation as a mechanism for the impaired EBV-specific B- and T-cell immune responses in CFS patients. Our findings in CFS have similarities to recent studies in systemic lupus erythematosus (SLE) as well, in which EBV reactivation is thought to play an important role in disease pathogenesis.
- "Finally, we think the altered pattern of the specific immune response to EBV may be suitable as a diagnostic marker for CFS."

Want to keep up with evolving science?

Check out [ME-CFS Evolving Science](#) on Facebook (you need to have a Facebook account).

About ME-CFS Evolving Science: ... "We are ME and CFS patients, from both sides of the Atlantic, with a genuine interest in the science of our diseases. Our aim is to bring you the best recent research news. Most of our posts are linking to the original scientific publications (with access to full text if freely available). We also post relevant commentaries from credible sources."

Fibromyalgia News & Developments

Save the Date – the FDA wants to hear from you!

The Fibromyalgia Patient-Focused Drug Development meeting, originally scheduled for last December 10, has been rescheduled to Wednesday, March 26, 2014. The meeting will be from 1:00 pm EDT – 5:00 pm EDT. [Learn more and register](#). Registration closes March 20, 2014.

The FDA is interested in obtaining patient input on the impact of fibromyalgia on daily life and patients' views on currently available therapies to treat the condition. In addition to providing input at the public meeting, patient stakeholders can provide their perspectives on the discussion questions through the public docket. The docket closes on May 26, 2014. [Find out more about what the FDA most wants to learn from patients and submit your comments](#)

This is an important opportunity to make your voice, as a patient, heard. The "Voice of the Patient" report will be widely circulated and provided to other government agencies as well as to drug developers.

Clinical trials for Fibromyalgia

[The Next Generation of Fibromyalgia Treatments – The Clinical Trials](#) (Health Rising by Cort Johnson, November 11, 2013) is an extensive and informative summary prepared by Cort Johnson that reviews current, recently completed, and upcoming clinical trials for a wide range of Fibromyalgia (FM) treatments. He has also included links to each clinical trial webpage.

Just a few of the drugs that are being studied for treatment of FM include:

- Droxidopa and Droxidopa/ Carbidopa
- Neurotropin (a drug used in Japan)
- Levetiracetam (brand name, Keppra)
- Ropinirole (brand name, Requip)
- Memantine (from a new class of drugs developed for Alzheimer's that block NMDA-like glutamate receptors)
- Paroxetine-CR (Paxil-CR) in patients without anxiety
- Propranolol (low-dose beta blocker)

The article also reviews novel therapies for FM such as Direct Transcranial (brain) Stimulation; Repetitive Transcranial Magnetic Stimulation (rTMS) Sessions; and RINCE —"Reduced Impedance Noninvasive Cortical Stimulation."

From Around the Web - Coping Tips - Dealing with difficult people

As a new year unfolds, it is a good time to reflect on the previous year, accentuate the positive, and take a closer look at situations which were hard to endure. It may help to work out a plan in advance on how to better tackle some of these uncomfortable situations. Although these articles are intended for the general public, they provide helpful tips on how to handle a variety of tricky situations.

- [Become Adept at Dealing With Difficult People and Avoiding Conflict](#) ~ Practical suggestions on how to respond to difficult people, especially those who cannot be easily avoided. Ongoing, negative relationships can be very damaging to one's health.

- [Conflict Resolution Mistakes To Avoid](#) ~ The author offers constructive and healthier ways to manage conflicts.

Advocacy News & Updates

The story of the "IOM contract" continues (see [ME/CFS Definitions and the Institute of Medicine](#)). The Committee has been "provisionally" selected and includes 8 ME/CFS-knowledgeable members, including several who signed the open letter to Dr. Kathleen Sibelius. We have found the staff supporting the Committee's work to be very receptive and open to learning about the complex issues and history surrounding this illness.

The first meeting of the Committee was held on January 27-28, 2014, and included a 4½ hour public session on the first day. Our Association, along with other patient organizations and advocates, was invited to make a brief presentation to the panel addressing the question, "What is the most important aspect or information that this committee should consider throughout the course of the study?" Since we have been working on issues around pediatric ME/CFS our talk focused on the importance of looking at ME/CFS in children and adolescents as a separate group from adults (not a "sub-group") and a plea to plan appropriate ME/CFS education for pediatricians and school nurses. [See our comments](#).

Other presentations to the Committee included an opening statement from Dr. Nancy Lee, the Designated Federal Official for the Chronic Fatigue Syndrome Advisory Committee (CFSAC), the FDA's "Voice of the Patient" report, as well as descriptions of the CDC's multi-site clinical study and the NIH "evidence-based methodology workshop." There were also 15 open 3-minute slots for members of the public during which many individual advocates spoke for themselves or read statements from others. We expect the full webcast to be available on the IOM CFS meeting site in the near future.

This process provides an on-going opportunity for the Committee to hear from the ME/CFS community about the many important issues which affect patients and their families as well as researchers and clinicians. We can only hope that they will listen and learn.

We are grateful to the Hennessey family and donations made in memory of Tom Hennessey for providing the funds to allow us to present in person at this important meeting.

Coming Up!
February 25: CDC Chronic Fatigue Syndrome (CFS)
Patient-Centered Outreach and Communication Activity (PCOCA)
Conference Call

Tuesday, February 25, 2014
3:00 pm - 4:00 pm EST

Call number: Participant Code: 1471493

MEETING AGENDA

- 3:00pm — Welcome and Telephone Overview
- 3:05pm Updates from CDC — Elizabeth Unger, PhD, MD, Branch Chief, Chronic Viral Diseases Branch, Centers for Disease Control and Prevention
- 3:15pm "CFS and Cognitive Function" — Gudrun Lange, Ph.D., Consultant Clinical Neuropsychologist, Pain and Fatigue Study Center Beth Israel Medical Center, NY, NY, Professor, Department of Physical Medicine and Rehabilitation Rutgers University
- 3:45pm — Questions from CFSPCOCA Call Mailbox for Guest Speaker and CDC

To get direct email notifications about these calls, please send an email to CFSPCOCACall@cdc.gov.

March 11: Next CFSAC Webinar

A Chronic Fatigue Syndrome Advisory Committee (CFSAC) Webinar is scheduled for March 11, 2014 from 12:00-5:00 PM Eastern Time.

The webinar's main purpose is to have more discussion around the potential recommendations coming from the two workgroups. We will provide an opportunity for those who had been scheduled for the December 10 public testimony (cancelled because of weather) to give their testimony. We will also have reports from the agencies who weren't able to give their report during the December webinar.

Further details to follow.

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If you like receiving this free newsletter every month, please consider supporting the Association by [becoming a member](#) .

We also welcome [volunteers](#) , especially people with basic computer skills who would like to learn something new.

You don't need to live in Massachusetts, or be ill, to be part of our Association! We welcome healthy family members and friends, as well as patients, as both members and volunteers.

Please pass this newsletter on to family, friends, and fellow patients! If you are receiving this copy from a friend, you can [sign-up here](#) to receive the newsletter yourself.