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## Massachusetts CFIDS/ME & FM Association News

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☐ ☐ PLEASE TAKE AN ☐ IMPORTANT PATIENT SURVEY ☐ ☐



☐ HELP BUILD A PATIENT POWERED RESEARCH NETWORK!

Please take a moment to complete a ***simple 5 question survey from the CFIDS Association of America (CAA)*** . The CAA

is partnering with

a number of organizations (ours included) to compete for twelve million dollars that will fund Patient Powered Research Networks in the USA. This is a HUGE opportunity for the ME/CFS and Fibromyalgia community and we need your help! Surveys must be completed by August 31st (US citizens only) and

**EVERY RESPONSE COUNTS!**

[Take the survey](#)

### MARK YOUR CALENDAR

1. **September 10, 2013** 3:00 pm - 4:00 pm (EST). Updates will be provided by Elizabeth Unger, PhD, MD  
Branch Chief, Chronic Viral Diseases Branch of the

To listen to the call, dial 1-888-946-3511 and enter the participant code when prompted: 602910  
6. Que  
s tion

s for the Guest Speakers and CDC can be only be submitted via email at  
[CFSPCOACall@cdc.gov](mailto:CFSPCOACall@cdc.gov)

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## SAVE THE DATE: Saturday, November 2, 2013 ☐☐

The Massachusetts CFIDS/ME & FM Association is delighted to welcome back **Dr. Anthony Komaroff** of the Harvard Medical School as guest speaker for our Fall 2013 lecture. The lecture will be held at the Morse Institute Library in Natick.

Anthony Komaroff, M.D. has written more than 200 journal articles and textbook chapters, was the editor for the best-selling book *The Harvard Medical School Family Health Guide*, and currently publishes [Ask Doctor K.](#), a health-oriented newspaper column which can be read on-line.

Well known for his work in the field of ME/CFS, Dr. Komaroff was selected by the Centers for Disease Control to participate in a number of Continuing Medical Education courses available to physicians on-line including the video lecture entitled "[Chronic Fatigue Syndrome: The Challenges in Primary Care](#)".

*Watch for more information about this event in our next newsletter!*

## STUDY FOR FIBROMYALGIA PATIENTS IN THE GREATER BOSTON AREA

If you are interested in enrolling in an Fibromyalgia study: Spaulding Rehabilitation Network Research Institute is currently enrolling study participants for a Fibromyalgia study involving a clinical trial of high-definition transcranial direct current stimulation. All participants enrolled will receive the treatment. This study is a follow-up to the initial study using this method for treating FM pain which showed a promising treatment. The study is being conducted at the Laboratory of Neuromodulation in Charlestown, MA. To learn more, [view the flyer](#) and the study's [Recruitment Document](#)

## NEW ON OUR WEBSITE

**Simmaron Research Wins in Funds for Research Campaign**—We are pleased to announce that Simmaron Neuroimmune Research, Incline Village, NV (Dr. Dan Peterson) received the most votes from our donors, and our collective contribution is being sent to them. [Read the article](#)

**New Book Review: Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition by Erica F. Verrillo** — For those of us looking for answers while living with CFS/ME or living with someone who suffers from it, the task can be especially daunting. For that reason alone, the recently published Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition by Erica F. Verrillo (only available in e-book format from Amazon) is an invaluable resource. [Read the Book Review](#)

## A potpourri of inspirational stories and writings

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The Association's website offers a large variety of helpful information on Coping with Chronic Illness.

Here are the two most recent additions to this useful patient resource:

Tips for Living with CFS and FM - In Real Life and in On-line Communities

While no one can completely escape negative or stressful situations, people with chronic

illnesses may find that stress, pain and illness can become intertwined. Even getting through activities of daily living, an easy task for someone in good health, will usually pose a significant challenge for individuals with chronic illness. So, it becomes essential that patients learn how to manage their time and energy as efficiently as they can, within the constraints of their illness. Patients will also need to examine and recalibrate their expectations. A new article posted on our website offers tips and strategies for managing expectations, making livable choices, growing beyond the illness and more.

[Read more](#)

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Does Procrastination Live Among CFS and FM Patients?

Is there such a thing as procrastination for those with Chronic Fatigue Syndrome (CFS)/Fibromyalgia (FM)?

*Do not yell all at once*

. For most people procrastination is a bad thing—but does it exist for us?

[Read the article](#)

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## ▯▯ NEWS FROM AROUND THE WEB

Unique immunologic patterns in fibromyalgia — This is an article published by a research team at the Department of Pathology/Research Resource Center at the University of Illinois, Chicago, IL which revealed important, objective findings which may offer diagnostic methodology in FM. They examined the cytokine responses to mitogenic activators of plasma and peripheral blood mononuclear cells (PBMC) taken from FM patients and these were found to be significantly lower than those of healthy individuals, implying that cell-mediated immunity is impaired in FM patients. This study points to a novel cytokine assay which reveals distinctive and valuable immunologic traits in FM. This study is available for free, as a full text article with tables.

[Access the article](#)

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Half Of Fibromyalgia Patients Have Evidence Of Nerve Damage — A short summary about research being done in Massachusetts that shows evidence of neuropathy in the skin biopsies of Fibromyalgia patients. Leading researcher of these studies, Anne Louise Oaklander, MD, PhD, director of the Nerve Injury Unit in the MGH Department of Neurology and corresponding author of the Pain paper states, “This provides some of the first objective evidence of a mechanism behind some cases of fibromyalgia, and identifying an underlying cause is the first

step towards finding better treatments."

[Read the summary](#)

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An Interview With Dr. Dan Peterson— This interview represents ME/CFS Alert Episode 48 in which Dr. Dan Peterson, Sierra Internal Medicine /Simmaron Research Institute, answers an array of questions about how he treats patients, research on the horizon, and other important topics affecting patients and their care. [View the video](#) or

[Read the article](#)

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The Simmaron ME/CFS Physicians Roundtable Pt. II: Talking Treatments — Dr. Peterson of Sierra Internal Medicine /Simmaron Research Institute, Dr. Klimas, the Director of the Center for Neuroimmune Studies at Nova Southeastern University, and Dr. Enlander, the Director of the Mt. Sinai ME/CFS Research Center discuss their treatment approach to ME/CFS.

[Read the article](#)

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## **ADVOCATES REQUEST CPET, NK CELL AND VIRAL TESTING IN CDC STUDY**

Our Association signed a recent letter to Dr. Beth Unger of the Centers for Disease Control (CDC) urging the CDC to include certain objective tests in their current multi-site assessment for CFS and ME— specifically the 2-Day Cardiopulmonary Exercise Test (CPET) known as the Stevens Protocol, and lab tests which measure Natural Killer (NK) Cell function and viral load, including enteroviruses. Each of the clinicians involved in the multi-site research study received a letter as well.

For more information, links to the letters sent, and a sample request that YOU can send yourself, please read the excellent article by Mark Berry on *Phoenix Rising*, entitled "[CDC Study Must Include CPET, NK Cell and Viral Testing, Advocates Insist](#)

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## SCHOOL HEALTH INSTITUTE 2013

Two MassCFIDS volunteers took our ME/CFS and FM exhibits and materials to the 2013 Northeastern University School Health Institute in Hyannis, MA, on August 6, where 275 school nurses were in attendance. Last year at this same conference we gave a one-hour presentation to all attendees, "Recognizing and Managing Children and Adolescents with Chronic Fatigue Syndrome in a School Setting," and also gave each attendee a copy of our *Pediatric ME/CFS: Resources for Patients, Parents, Schools and Clinical Practitioners, August, 2012* CD. This year we only "exhibited" but received a number of very positive comments from school nurses who saw the presentation last year. We gave out over 100 of the CDs to attendees who were not present last year, and many of the nurses also signed up for our school nurse newsletter.

## NEW AWARENESS CAMPAIGN FOR LYME DISEASE

A new awareness campaign has been started by the **International Lyme and Associated Diseases Society** (ILADS). The campaign is modeled after the "Act Up" campaign for AIDS that served to give them a voice and bring the change they needed.

[Read about the campaign](#)

## DID YOU KNOW?

***The symptoms of Lyme disease, Fibromyalgia, MS, and ME/CFS are very similar and vary from person to person.*** Symptoms might include fatigue, muscle and joint pain, brain fog, and stiff/crunchy neck.

For many, getting a good test for Lyme and other tick borne illnesses might reveal the real cause of their years of suffering. IGENEX labs in California is one lab offering some of the most sensitive testing for tick borne diseases and is often used by Lyme specialists. Many patients are (mis-)diagnosed with Fibromyalgia or MS, only to learn they actually have Chronic Lyme

Disease.

With proper treatment by a Lyme specialist, it is possible to improve a patient's quality of life through treatment. In some cases, the treatment can be a long process and should be ideally conducted by a Lyme specialist who thoroughly understands the complexities of Lyme and other tick borne illnesses.

Some great organizations advocating for and researching Lyme and other tick borne diseases are:

[Lyme Disease Association, Inc .](#)

[The International Lyme and Associated Diseases Society](#)

[Tick Borne Disease Alliance](#)

[Lyme Research Alliance](#)

[Sturbridge Lyme Awareness of MA](#)

These organizations offer informative websites and resources to learn more so you can be informed about how to get a good test and where to go for help and support.

*Information contributed by Trish McCleary from Sturbridge Lyme Awareness of Massachusetts (S-L-A-M.org)*

## SEPTEMBER IS PAIN AWARENESS MONTH

September is "**Pain Awareness Month**," a time when organizations and patient advocates focus on raising public awareness about chronic pain and pain management.

The first pain awareness month was established in 2001 through the efforts of a coalition of groups led by the [American Chronic Pain Association](#) (ACPA).

A variety of information is available on the Association's website regarding pain and pain management. [View a summary of recent articles](#) .



### ☐ VOLUNTEERS NEEDED

Do you enjoy working on the computer and/or would you like to write articles for a patient website or newsletter? Can you help in some other way? We are in need of new volunteers, sick or well, who are willing to donate time and energy to help our all-volunteer Association.

A few hours a month is all it takes and most volunteer work can be done from the comfort of your own home. If you have an ability or interest you'd like to share (or know someone else who does), please be sure to let us know. Help is needed in the following areas:

- Writing for our website and newsletter;
- Light technical help with the website (posting articles, etc.);
- Help with design and set-up of a "new and improved" website;
- Help with development of new features for our member database;
- Help with Google Analytics and/or Search Engine Optimization.

We can provide basic training in any area of interest (by phone, computer, or in person) based



on your availability. [Find out more](#) .

**Add Your Voice by Becoming a Member** ~ Through the Association, individual patients and friends/family join together and speak with a stronger voice on behalf of their needs. For those who can afford to help, the membership donation enables us to respond to the many needs of the patient community. For those who are unable to make a donation, courtesy membership is also available. [Become a member](#) .

**Forward this newsletter to friends and family.** By doing so, you call attention to the Association's efforts and provide others with an opportunity to learn about the debilitating effects of CFIDS/ME and FM. If this newsletter has been forwarded to you and you'd like to receive future issues directly, [sign up here](#) .

**THANK YOU FOR YOUR SUPPORT!**

*Disclaimer: □ Articles and links in this newsletter do not indicate an “endorsement” □ of any kind by the Massachusetts CFIDS/ME □ & FM Association. □ Ideas and opinions expressed in other associated or linked sites are those of the individual authors. The Massachusetts CFIDS/ME & FM Association takes no responsibility for their content. □*

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Massachusetts CFIDS/ME & FM Association

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