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CFIDSLink is now Research1st News

## NEW @ RESEARCH1st

The U.S. Food and Drug Administration (FDA) declined to approve **Hemispherx Biopharma's** application to market its experimental drug, **Ampligen**, for CFS. The decision, announced on Feb. 4 by Hemispherx, was a great disappointment to many in the CFS community, especially those who have benefited from the drug. Read more about the decision, attention it attracted, and the long history of this drug: <http://bit.ly/ampligen-decision>



Ampligen declined FDA approval

In the second installment of our two-part series featured last month, **Peter Rowe, M.D.**, and colleagues describe their study of impaired nerve mechanics and function in CFS. This article also describes their approach to manual physical therapy as an adjunct to medical care that may help improve mobility and some symptoms. Part 1: <http://bit.ly/manual-tx-pt-1> and Part 2: <http://bit.ly/manual-tx-pt-2>

Three studies in the NYC region are **recruiting participants** with CFS and healthy volunteers. These three studies are registered and approved by institutional review boards. Dr. Marvin Medow at New York Medical College (Valhalla, NY) is studying brain fog in CFS among patients with and without orthostatic intolerance. Dr. Benjamin Natelson at Beth Israel Medical Center (NY, NY) is recruiting subjects for two studies: one will attempt to better characterize CFS as part of a CDC-sponsored study. The second study will test for various brain abnormalities. More information at <http://bit.ly/3-NY-studies>



Benjamin Natelson, MD



Marvin Medow, PhD

Subscribe to our Research1st blog at <http://bit.ly/R1st-blog>



## JOURNAL HIGHLIGHTS

### LOW-DOSE NALTREXONE SHOWS PROMISE:

Researchers at Stanford University report that a study of 31 women with fibromyalgia (FM) shows promising results for low-dose naltrexone to reduce pain and improve mood and satisfaction with life. The study used a cross-over design and participants received medication for 12 weeks and placebo for 4 weeks with a 4-week follow-up period. Abstract from *Arthritis & Rheumatism*: <http://bit.ly/11EYqY5>

#### Low-Dose Naltrexone for the Treatment of Fibromyalgia

Findings of a Small, Randomized, Double-Blind, Placebo-Controlled, Counterbalanced, Crossover Trial Assessing Daily Pain Levels



"The preliminary evidence continues to show that low-dose naltrexone has a specific and clinically beneficial impact on fibromyalgia pain. The medication is widely available, inexpensive, safe, and well-tolerated."



*Arthritis & Rheumatism*  
 Volume 65, Issue 2, pages 529-538, FEB 2013 DOI: 10.1002/art.37734  
<http://onlinelibrary.wiley.com/doi/10.1002/art.37734/full#ftot>

### GUT TISSUE BIOPSY SAMPLES STUDIED:

Researchers in Belgium, Russia, Hungary and the U.S. (Whittemore Peterson Institute) reported results of a preliminary analysis of de-identified gut tissue obtained from 12 patients meeting Canadian and Fukuda definitions for ME/CFS and CFS and 8 healthy subjects. Tissue samples were obtained during clinical diagnostic procedures and limited information was available about the subjects. Eight of 12 individuals with ME/CFS displayed immunoreactivity to human endogenous retroviral (HERV) proteins localized to cells with plasmacytoid dendritic cell characteristics. No immunoreactivity was observed in control tissue. The authors suggest that "the prospect of an involvement of HERVs and plasmacytoid dendritic cells in ME pathology provides an opportunity for more directed studies into the immune dysregulation associated with this disease." A larger and properly controlled study is needed. Full text of the paper published in *In Vivo*: <http://bit.ly/XxXDTI>

**VIRAL STUDY FINDS NO DIFFERENCES:** A team of researchers from Tufts University and Harvard Medical School has published results of a study of 39 CFS patients and 9 healthy controls to test for evidence of human endogenous retrovirus K18 (HERV K18) and reactivation with HHV-6 and HHV-7. No differences were found between cases and controls. Abstract from *Clinical Infectious Diseases*: <http://bit.ly/ZgyCQr>

**FM AS A SPECTRUM DISORDER:** Researchers in Kansas and Germany report results of a large population survey of 2,445 people selected randomly from the German population. 2.1% of the population met 2010 criteria for FM. Prevalence was similar in women and men, a difference from past studies that showed more women than men had FM. They found a spectrum of severity, "The symptoms that characterize fibromyalgia exist in a continuum from none to very severe across all people in the population." Summary from MedPage Today: <http://bit.ly/W3pnC9> and abstract from *Arthritis Care & Research*: <http://bit.ly/Zg98im>

**RESEARCH RECOMMENDATIONS POSTED:** A summary of the Aug. 2012 NIH Workshop on Chronic Overlapping Pain Conditions, including recommendations for future research, has been posted on the NIH's website at <http://1.usa.gov/W4pauK>

Keep up with journal highlights on our Research1st website at <http://bit.ly/journal-hilites>

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## POLICY MATTERS

**SERIOUS UNMET NEED:** In the wake of Ampligen, the Association joined with requests for action of Dr. Howard Koh, and the leaders of Hemispherx to Read more from our CEO:



the disappointing decision on other advocates to make Assistant Secretary of Health, advance drug discovery for CFS. <http://bit.ly/unmet-need>

**SOUGHT:** The federal CFS Advisory Committee (CFSAC) is soliciting nominations for the addition of three ME/CFS organizations to join the committee as non-voting liaison representatives. Organizations selected from the nominees will contribute to discussion of research, diagnostics, treatments, public and professional education, and strategies to improve the quality of life of people living with ME/CFS. Nominations are due on Feb.

**NON-VOTING LIAISON REPS**

22, 2013. The CFIDS Association will apply for one of these positions. For more information, please see the Federal Register notice: <http://1.usa.gov/10WqbLI>

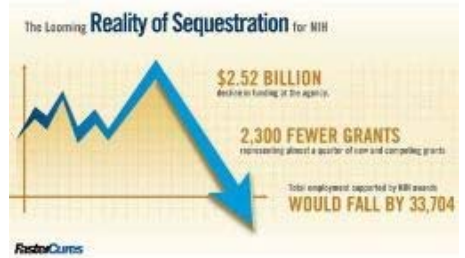
**CFSAC UNDER SCRUTINY:** A posting of "high-priority recommendations for ME/CFS" by staff of the CFSAC prior to its public discussion has come under scrutiny-first by advocate Jennie Spotila and, at her request, Public Citizen, a national watchdog organization. Jennie's post: <http://bit.ly/Zn48wh> and Public Citizen's letter to HHS: <http://bit.ly/15q2Xg2>



Federal CFS Advisory Committee

**DRUG DEVELOPMENT WORKSHOP:** In April the Food and Drug Administration will sponsor a workshop about drug development and clinical outcome measures in ME and CFS. We'll share additional details as they become available. The FDA has archived information about drug development in ME/CFS here: <http://1.usa.gov/N1zk2S>

**BUDGET CUTS THREATEN MEDICAL RESEARCH:** Across-the-board cuts to federally-funded programs are slated to take effect on March 1 unless Congress acts. Hundreds of professional organizations, advocacy groups and research institutions have voiced deep concerns about the lasting effects "sequestration" will have on promising research and the next generation of scientists. Learn more about what you can do to help inform lawmakers about the need to protect research investments at *FasterCures'* Sequestration Station: <http://bit.ly/WXCh3g>



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## OTHER NEWS & EVENTS

**Share your story** with our newest staff member, engagement manager [Leigh Reynolds](#), and help shape our communications outreach by responding to this 26-item survey about ways in which CFS impacts your life: <https://www.surveymonkey.com/s/N8B2QB7>

The front page of the Feb. 16 edition of the *San Francisco Chronicle* highlights CFS and anguish over the lack of approved treatments, particularly the recent decision by FDA to decline approval for Ampligen: <http://bit.ly/WOUVKw>

**San Francisco Chronicle**  
Chronic fatigue patients frustrated with FDA  
Eric Alday



**BioWorld**, a daily news service for the pharma industry, features an interview with CFIDS Association CEO Kim McCleary about Ampligen and how to improve chances for advancing the science and approval for the drug: <http://bit.ly/XxwNYy>

The March issue of **DISCOVER** magazine includes a 6-page article titled, "Chasing the Shadow Virus," by Hillary Johnson. The piece retraces the linking and de-linking of XMRV and CFS. The issue is on newsstands now; the article is not available online but you can view the table of contents:

<http://discovermagazine.com/2013/march>



A detailed article about CFS appeared in the Feb. 5, 2013 edition of the *South China Morning Post* (Hong Kong): <http://bit.ly/11pQABm>

Dr. Eleanor Stein of the University of Calgary describes the differences between ME, FM and known psychiatric conditions in this recent article written for *Psychiatric Times*: <http://bit.ly/Y9QS9B> (free registration required to view the article)

Video recordings from the Jan. 26, 2013 **CFS/GWI conference** hosted by the NOVA Southeastern University's Institute for Neuro-Immune Medicine are now available: <http://bit.ly/U2ryUv>

CBS Miami announces the opening of **Dr. Nancy Klimas' new clinic** at NOVA Southeastern University: <http://miami.cbslocal.com/2013/02/12/nova-southeastern-to-treat-people-with-chronic-fatigue-gulf-war-illness/>

**Invest in ME**, a U.K. charity, will host IIME8, "Infection, Immunity and ME," in Westminster, London on May 31, 2013. More information: <http://bit.ly/YGhQnN>

For **daily updates** about research, policy and media, join us on [Facebook](#) and follow us on [Twitter@plzsolvecfs](#).

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## The CFIDS Association of America

### Our Mission:

For CFS to be widely understood, diagnosable, curable and preventable.

### Our Strategy:

To stimulate research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private and commercial investment.

### Our Core Values:

To lead with integrity, innovation and purpose.

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The CFIDS Association of America | PO Box 220398 | Charlotte | NC | 28222-0398