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OFFER E-NEWS

March 2015

OFFER E-NEWS is a free monthly newsletter providing information on upcoming education meetings, conferences, and other ME/CFS & FM events or programs that may be of interest. It also includes links to what's new on the OFFER website, help in managing symptoms, information about local researchers looking for participants, and current articles in the news.



OFFER Education Meeting

"New Clinical Definitions for ME/CFS"

Lucinda Bateman, MD

Wednesday, March 4, 2015 at 7:00 p.m.

In 2001 Dr. Bateman founded the Fatigue Consultation Clinic (FCC) in Utah, specializing in the diagnosis, treatment, and study of ME/CFS and FM. She has become an internationally respected expert in the field.

The FCC has been recruited to participate in a number of national research projects due to her expertise in this area. Dr. Bateman is a research partner with the University of Utah, CDC, Chronic Fatigue Initiative, Solve ME/CFS Initiative, and major pharmaceuticals such as Pfizer, Lilly and Merck.

Location:

Salt Lake County Complex, North Building, 2001 S. State Street, SLC, UT

Park in the northeast corner of the complex.

To view the remaining 2015 Education Meeting Schedule, [click here](#).

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Gov. Herbert's Healthy Utah Plan Rally/March 5th

Where: Utah State Capitol, Capitol Rotunda

When: Thursday, March 5th

Time: 12:00 p.m. to 2:00 p.m.

What: Gov. Herbert's Healthy Utah Plan **passed the Utah State Senate**, but now the leadership of the House of Representatives is claiming that they will not hear the Healthy Utah bill—doing nothing instead. We are holding this rally in the **Capitol Rotunda from 12-2pm on Thursday, March 5th** to tell the Utah House of Representatives that we want an open and fact-based hearing on Healthy Utah.

If you're having trouble receiving each monthly issue of the E-News, make sure to add enews@offerutah.org to your approved sender list, address book, or white list it. If that doesn't correct the problem, [click here](#), or go to www.offerutah.org/enewssubscribe.html, and resubscribe.

Please see flyer for the rally and social media image at:

<http://www.offerutah.org/healthyutah.html>

Share on Facebook, Twitter, and Email.

This is a matter of people, and of process. Let the bill be heard!

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Bateman-Horne Center of Excellence: Update

Planting Seeds of Hope for ME/CFS and FM



OFFER is excited to announce the hiring of Allan Ainsworth as Chief Executive Officer/President to lead this effort. Dr. Ainsworth holds a PhD in medical anthropology from the University of Utah. He was the founder and Executive Director of the Fourth Street Clinic, a top ten nationally ranked health care for homeless community health center in Salt Lake City for 24 years. In 2011 Dr. Ainsworth was selected by Ernst & Young as their prestigious Social Entrepreneur of the Year and in October of 2014 the University of Utah School of Medicine Alumni Association recognized Dr. Ainsworth with the Distinguished Humanitarian Award for his commitment and service. His vision for this task can be summed up as follows:

The Centers of Excellence will be designed:

- To serve the needs of people who have been previously undiagnosed, misdiagnosed or under-diagnosed for the diseases of SEID (signifying Systemic Exertion Intolerance Disease, formerly known as Chronic Fatigue Syndrome) and FMS);
- To assess, diagnose and treat these diseases in the general population;
- To provide education and advocacy, and increase public visibility for these populations;
- And to be centers of research and clinical knowledge for clinical providers who seek to improve their skills in these areas of disease.

We will keep you informed of our progress.

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Lunch and Learn

NEW MONTHLY EVENT coordinated by OFFER

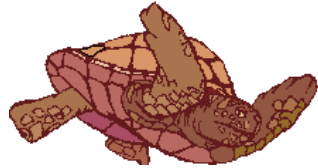
Sixteen SEID (formerly ME/CFS) and FMS people joined together for our second *Lunch and Learn*. Three people came with a supportive friend or family member -- two of those were husbands! We all applauded that. Those who attended all agreed the contributions from each person were very worthwhile. We hope each person will continue to come and bring a friend.

The next L 'n L will be on the 3rd Wednesday, March 18, at 11:30 a.m. at Brio Tuscan Grille at Fashion Place Mall, 6173 South State Street, Murray, UT.

For the cost of your own lunch (your choice from the menu), you can enjoy camaraderie and the chance to learn from each other. This is an informal way to socialize, eat LUNCH, and LEARN something about SEID (formerly ME/CFS) and FM. Anyone who is hungry and interested in learning more about SEID (formerly ME/CFS) and FM is welcome to attend.

RSVP: Please RSVP on the "OFFER Utah" Facebook page:
<https://www.facebook.com/OFFERUtah?ref=hl>.

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"We delight in the beauty of the butterfly, but rarely admit the changes it has gone through to achieve that beauty."

Author: Maya Angelou

In the News

The Pain Brain: Hippocampal Atrophy Found in Fibromyalgia

By Cort Johnson

February 16, 2015

Health Rising

<http://www.cortjohnson.org/blog/2015/02/16/pain-brain-hippocampal-atrophy-found-fibromyalgia/>

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness

Institute of Medicine *of the National Academy of Sciences*

February 10, 2015

[http://www.iom.edu/Reports/2015/ME-CFS.aspx?](http://www.iom.edu/Reports/2015/ME-CFS.aspx?utm_source=IOM+Ongoing+Email+List+(Consensus+Studies+and+Upcoming+Meetings)&utm_campaign=1d9c18b8c0-2_25_15_Listserv_IOM_Report_MECFS_Guide_Clinicians&utm_medium=email&utm_term=0_5e3a5cfc5c-1d9c18b8c0-180322925)

[utm_source=IOM+Ongoing+Email+List+](http://www.iom.edu/Reports/2015/ME-CFS.aspx?utm_source=IOM+Ongoing+Email+List+(Consensus+Studies+and+Upcoming+Meetings)&utm_campaign=1d9c18b8c0-2_25_15_Listserv_IOM_Report_MECFS_Guide_Clinicians&utm_medium=email&utm_term=0_5e3a5cfc5c-1d9c18b8c0-180322925)

[\(Consensus+Studies+and+Upcoming+Meetings\)&utm_campaign=1d9c18b8c0-](http://www.iom.edu/Reports/2015/ME-CFS.aspx?utm_source=IOM+Ongoing+Email+List+(Consensus+Studies+and+Upcoming+Meetings)&utm_campaign=1d9c18b8c0-2_25_15_Listserv_IOM_Report_MECFS_Guide_Clinicians&utm_medium=email&utm_term=0_5e3a5cfc5c-1d9c18b8c0-180322925)

[2_25_15_Listserv_IOM_Report_MECFS_Guide_Clinicians&utm](http://www.iom.edu/Reports/2015/ME-CFS.aspx?utm_source=IOM+Ongoing+Email+List+(Consensus+Studies+and+Upcoming+Meetings)&utm_campaign=1d9c18b8c0-2_25_15_Listserv_IOM_Report_MECFS_Guide_Clinicians&utm_medium=email&utm_term=0_5e3a5cfc5c-1d9c18b8c0-180322925)

[medium=email&utm_term=0_5e3a5cfc5c-1d9c18b8c0-](http://www.iom.edu/Reports/2015/ME-CFS.aspx?utm_source=IOM+Ongoing+Email+List+(Consensus+Studies+and+Upcoming+Meetings)&utm_campaign=1d9c18b8c0-2_25_15_Listserv_IOM_Report_MECFS_Guide_Clinicians&utm_medium=email&utm_term=0_5e3a5cfc5c-1d9c18b8c0-180322925)

[180322925](http://www.iom.edu/Reports/2015/ME-CFS.aspx?utm_source=IOM+Ongoing+Email+List+(Consensus+Studies+and+Upcoming+Meetings)&utm_campaign=1d9c18b8c0-2_25_15_Listserv_IOM_Report_MECFS_Guide_Clinicians&utm_medium=email&utm_term=0_5e3a5cfc5c-1d9c18b8c0-180322925)

Brief Report: Excitatory and Inhibitory Brain Metabolites as Targets of Motor Cortex Transcranial Direct Current Stimulation Therapy and Predictors of Its Efficacy in Fibromyalgia

By Bradley R. Foerster, et.al.

January 28, 2015

Arthritis & Rheumatology

<http://onlinelibrary.wiley.com/doi/10.1002/art.38945/abstract>

Utah doctor helps to legitimize chronic fatigue as an actual disease

By Wendy Leonard

February 10, 2015

Deseret News

<http://www.deseretnews.com/article/865621577/Utah-doctor-helps-to-legitimize-chronic-fatigue-fibromyalgia.html?pg=all>

A Disease Doctors Refuse to See

Chronic Fatigue Syndrome Needs Effective Treatments

By Julie Rehmeyer

February 25, 2015

The New York Times

<http://www.nytimes.com/2015/02/25/opinion/understanding-chronic-fatigue.html?smid=fb-share&r=0>

Impact of Invalidation and Trust in Physicians on Health Outcomes in Fibromyalgia Patients

By Carroline P. Lobo, MS, et.al.

October 9, 2014

Primary Care Companion for CNS Disorders

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4321014/>

The Biggest Chronic Fatigue Syndrome Treatment Trial Begins: Fluge/Mella On Rituximab

By Cort Johnson

January 20, 2015

Simmaron Research

<http://simmaronresearch.com/2015/01/chronic-fatigue-syndrome-rituximab-fluge-mella/>

Modified 2010 Criteria for Fibromyalgia Boosts Prevalence

February 09, 2015

Neurology Advisor

<http://www.neurologyadvisor.com/fibromyalgia-diagnosis-criteria-prevalence/article/397077/>

The Case for Centers of Excellence in Chronic Fatigue Syndrome

By Cort Johnson

February 1, 2015

Health Rising

<http://www.cortjohnson.org/blog/2015/02/01/case-centers-excellence-chronic-fatigue-syndrome/>

Additional links to coverage of Institute of Medicine Report:

<http://jama.jamanetwork.com/article.aspx?articleid=2118591>

<http://annals.org/article.aspx?articleid=2118972>

<http://www.washingtonpost.com/news/to-your-health/wp/2015/02/10/chronic-fatigue-syndrome-is-a-real-condition-not-a-psychological-illness-expert-panel-says/>

<http://news.sciencemag.org/health/2015/02/goodbye-chronic-fatigue-syndrome-hello-seid>

<http://www.thestarphoenix.com/health/Seeking+redefine+chronic+fatigue+syndrome+advisory+group+urges/10801848/story.html>

<http://www.today.com/health/chronic-fatigue-syndrome-real-dont-call-it-panel-says-2D80484902>

<http://www.nbcnews.com/nightly-news/chronic-fatigue-syndrome-gets-new-name-n305191>

http://www.huffingtonpost.com/2015/02/12/chronic-fatigue-new-name_n_6671122.html

http://www.cdc.gov/genomics/public/features/chronic_fatigue.htm

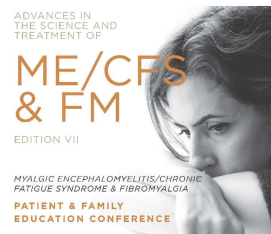
<http://www.npr.org/blogs/health/2015/02/11/385465667/panel-says-chronic-fatigue-syndrome-is-a-disease-and-renames-it>

<http://time.com/3706453/chronic-fatigue-syndrome-systemic-exertion-intolerance-disease/>

<http://www.nature.com/news/us-panel-redefines-chronic-fatigue-syndrome-1.16905>

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OFFER Patient & Family Conference



Some of the videos from "Advances in the Science and Treatment of ME/CFS and Fibromyalgia" Edition VII OFFER Provider/Patient & Family Conferences have been posted on YouTube, with more to follow in the coming weeks.

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New on the OFFER Website: Painless Donating!

Shop at AmazonSmile and Amazon will make a donation to OFFER at no extra cost to you!

Go to: <https://smile.amazon.com/ch/87-0687610>

Shop at your favorite stores through iGive.com and OFFER will receive a donation (usually about 3%) at no extra cost to you!

Go to: <http://www.igive.com/welcome/lp9/cr49.cfm>

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Info Links & Social Media

Management of Fibromyalgia Syndrome: Review of Evidence

Akiko Okifuji and Bradford D. Hare

Published online September 21, 2014

Pain and Therapy
NCBI>Literature>PubMed Central (PMC)
Go to: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4107911/>

Guest Blog: Dr. Peter Rowe - Is The Physical Examination Normal in CFS? Part 1

September 5, 2014

Solve ME/CFS Initiative

Go to: <http://solvecfs.org/guest-blog-dr-peter-rowe-is-the-physical-examination-normal-in-cfs-part-1/>

Guest Blog: Dr. Lary Baldwin on Post-Exertional Debility in ME/CFS

May 14, 2014

Solve ME/CFS Initiative

Go to: <http://solvecfs.org/guest-blog-dr-larry-baldwin-on-post-exertional-debility-in-mecfs/>

Fatigue Consultation Clinic

Lucinda Bateman, M.D., at the Fatigue Consultation Clinic in Salt Lake City, is currently giving new patient priority to adolescents ages 12-17, who have symptoms of fibromyalgia. Please call (801) 359-7400 to initiate a visit. Their website is: <http://www.fcclinic.com>.

OFFER's Website

Visit OFFER's website for additional resources to important health information and CFS/FM research studies at: www.offerutah.org under Resources.

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Current Patient Studies

New Research Studies

Fatigue Consultation Clinic is conducting a **non-drug** approach for **fibromyalgia** currently being evaluated as part of a new clinical research study. NeuroPoint delivers gentle electrical stimulation to specific areas of the brain that may be involved in overactive pain perception for fibromyalgia sufferers. This stimulation is designed to reduce this over activity in a way that might help reduce the perception of pain. To be eligible for the NeuroPoint Clinical study, you must meet specific criteria.

If you're interested or want to learn more, contact the research department at 801-532-8311. **Call soon**, available space is limited.

University of Utah is recruiting females with Fibromyalgia and healthy volunteers for sleep and pain sensitivity study

Researchers in the Department of Anesthesiology are conducting an IRB approved study for females 21-65 years of age that have Fibromyalgia and do not exercise regularly (less than 30 minutes per week). We are also recruiting healthy volunteers that do not have chronic pain and do not exercise regularly. The purpose of this research project is to examine if sleep is related to thermal and ischemic pain sensitivity and cellular aging in women with Fibromyalgia compared to healthy volunteers. After an initial visit, you will monitor your sleep using a wrist watch for seven days then return for a single testing visit where we will evaluate two different methods to test pain tolerance and threshold. **There will be compensation for your time and participation.**

For more information please contact the study coordinator at (801)

581-4232 or e-mail painresearchstudies@hsc.utah.edu
Go to: <http://healthsciences.utah.edu/pain-research-center/studies/pain-and-sleep-study.php>.

The Synergy Trial

A Clinical Trial Investigating a Combination of a CFS Nutrient Formula plus a Currently Available Medication to Treat *Chronic Fatigue Syndrome*

The Fatigue Consultation Clinic is one of four clinics nationally that are participating in this study.

Fatigue Consultation Clinic

Dr. Bateman's Research Team continues to seek research participants. They are currently enrolling in:

- **The Synergy Trial**
- Three drug studies for adolescents with FM
- One drug study for adults with FM
- A number of biomarker studies for patients with CFS.

The link to the FCC Research Department page is:
<http://www.fcclinic.com/research.htm>.

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Volunteer

OFFER is always looking for individuals willing to help accomplish our mission statement: to educate, advocate and help fund promising research. OFFER is a volunteer organization and almost all of us deal with ME/CFS and/or Fibromyalgia on a daily basis. We understand limitations! Many of these jobs can be done from home, using a personal computer with an internet connection. If you have skills you'd like to share, please let us know.

These are some areas where we currently need volunteers:

1. Help with our web presence. Experienced or willing to learn.
 - Adobe Flash
 - Adobe Dreamweaver
 - HTML
 - Social Media, including Facebook, YouTube, Google+
2. AV experience. OFFER has the equipment.
 - Filming
 - Editing
3. Patients, caregivers and clinicians who would be willing to tell their story on video for 10-15 minute segments.

If you would like to volunteer in any of these areas, please go to: <http://www.offerutah.org/volunteer.html>.

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