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OFFER E-NEWS

April 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

"The Art of Acceptance"

Jill Cook

Wednesday, April 1, 2015 at 7:00 p.m.

Jill Cook has been coping with ME/CFS/SEID. She will share her journey of adjusting to her new reality of being chronically ill. Her message will be very inspirational.

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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Bateman-Horne Center: Update

OFFER, a Utah-based, charitable, 501(c)(3), non-profit organization since 2002, is excited to announce that our plans to expand our efforts and broaden our focus are rapidly taking shape. Our new effort requires a new name to better reflect the broader goals of OFFER, encompassing all that we have been doing for the last 13 years and adding the resources to significantly address the needs of underserved patients for clear diagnoses, state of the art treatment options and robust research capabilities that have been sorely lacking in the state of Utah, as it has in most of the country. This center of excellence will encompass four key areas that are reflected in the acronym: CARE. These are patient Care, patient Advocacy, Research, and Education. Absorbing and expanding the Fatigue Consultation Clinic into OFFER, we will be transitioning to the new name reflected in our new logo, making its first public appearance below:



Bateman Horne Center

CARE | ADVOCACY | RESEARCH | EDUCATION

As we announced last month, Allan Ainsworth, our new Chief Executive Officer/President is leading 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 Allan 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 continue keep you informed of our progress.

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Lunch and Learn

NEW MONTHLY EVENT coordinated by OFFER

At the March gathering, Diane Sorensen presented thoughts from Viktor Frankl's book *Man's Search for Meaning*. According to Frankl, "We can discover this meaning in life in three different ways: (1) by creating a work or doing a deed; (2) by experiencing something or encountering someone; and (3) by the attitude we take toward unavoidable suffering" and that "everything can be taken from a man but one thing: the last of the human freedoms—to choose one's attitude in any given set of circumstances."

The next L'n L will be on the 3rd Wednesday, April 15, at 11:30 a.m. at the Olive Garden, 6305 South State Street, Murray, UT. This is at Fashion Place Mall.

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 relating to FM and SEID (formerly ME/CFS).

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

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"Hardship often prepares an ordinary person for an extraordinary destiny."

Author: C.S. Lewis

In the News

Is Fibromyalgia A Mitochondrial Disorder?

By Cort Johnson

March 4, 2015

Health Rising

<http://www.cortjohnson.org/blog/2015/03/04/is-fibromyalgia-a-mitochondrial-disorder/>

Distinct plasma immune signatures in ME/CFS are present early in the course of illness

By Mady Hornig, José G. Montoya, Nancy G. Klimas, Susan Levine, Donna Felsenstein, Lucinda Bateman, Daniel L. Peterson, C. Gunnar Gottschalk, Andrew F. Schultz, Xiaoyu Che, Meredith L. Eddy, Anthony L. Komaroff, W. Ian Lipkin

Science Advances

February 27 2015: Vol. 1 no. 1 e1400121

DOI: 10.1126/sciadv.1400121

American Association for the Advancement of Science

<http://advances.sciencemag.org/content/1/1/e1400121>

Pfizer pain drug Lyrica fails study in adolescents with fibromyalgia

Reuters | Health

March 12, 2015

Reuters

<http://www.reuters.com/article/2015/03/12/us-pfizer-study-idUSKBN0M82O620150312>

Fuse FM hold 24-hour charity broadcast

Fuse FM staged a 24-hour broadcast for Action for ME a charity which offers support for people suffering with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome.

By Kathryn Murray

March 29, 2015

The Mancunian

<http://mancunian.com/2015/03/10/fuse-fm-hold-24-hour-charity-broadcast/>

Study shows why exercise magnifies exhaustion for chronic fatigue syndrome patients

March 12, 2015

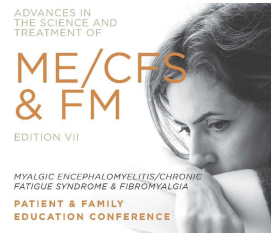
Category: Health, Research

University of Florida

<http://news.ufl.edu/archive/2015/03/study-shows-why-exercise-magnifies-exhaustion-for-chronic-fatigue-syndrome-patients.html>

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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. Larry 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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