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# OFFER E-NEWS

January 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

### "Panel of the Parents of ME/CFS and Fibromyalgia Patients"

Panel

Wednesday, January 7, 2015 at 7:00 p.m.

#### IN THIS ISSUE

- ☐ [OFFER Education Meeting](#)
- ☐ [New Fatigue Patient Study](#)
- ☐ [Shauna Bateman Horne Clinic](#)
- ☐ [OFFER Patient & Family Conference](#)
- ☐ [Painless Donating](#)
- ☐ [In the News](#)
- ☐ [Info Links & Social Media](#)
- ☐ [Current Patient Studies](#)
- ☐ [Volunteer](#)

#### 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](#).

[Back to top](#)

#### E-NEWS QUICK LINKS

- ☐ [Conferences](#)
- ☐ [Donate](#)
- ☐ [E-News Archives](#)
- ☐ [Education Meetings](#)
- ☐ [E-news Subscriptions](#)
- ☐ [OFFER's BLOG: Linda's Corner](#)
- ☐ [Volunteer](#)

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## New Fatigue Consultation Clinic Patient Study

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.**

[Back to top](#)

## The Shauna Bateman Horne

# Clinic

## Planting Seeds of Hope for ME/CFS and FM



### **The Organization for Fatigue & Fibromyalgia Education & Research (OFFER) Letter of Intent:**

Right now, in the state of Utah alone, there are thousands of people with Chronic Fatigue Syndrome (also called Myalgic Encephalomyelitis or ME/CFS) and Fibromyalgia (FM) who have not been properly diagnosed or offered effective treatments. Unfortunately, many are disabled by their illness. An important reason for the lack of accurate and timely diagnosis and effective treatment is clearly stated on the U.S. Centers for Disease Control and Prevention (CDC) website: "Researchers have not yet identified what causes CFS, and there are no tests to diagnose CFS." "Despite a vigorous search, scientists have not yet identified what causes CFS." ... To read the full letter, please go to <http://www.offerutah.org/sbhcenterofexcellence.html>.

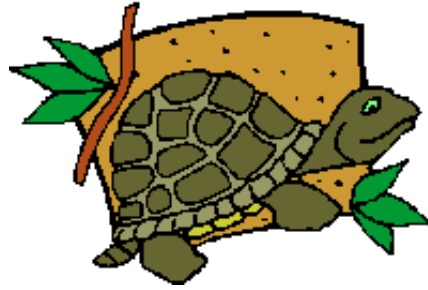
Watch Dr. Lucinda Bateman's initial announcement that OFFER has set the goal of creating a new clinical and research Center of Excellence. The Shauna Bateman Home Clinic for ME/CFS & FM at: <http://offerutah.org/bateman5.17.htm>.

**[Back to top](#)**

## OFFER Patient & Family Conference



Videos from "Advances in the Science and Treatment of ME/CFS and Fibromyalgia" Edition VII OFFER Provider/Patient & Family Conferences will be posted on the OFFER website and YouTube in the coming weeks.



*"For beautiful eyes, look for the good in others; for beautiful lips,  
speak only words of kindness; and for poise, walk with the  
knowledge that you are never alone."*

Author: Audrey Hepburn

## In the News

### **Lack of Knowledgeable Healthcare Access for Patients with Neuro-endocrine-immune Diseases**

By Tina M. Tidmore et al

December 9, 2014

[www.prohealth.com](http://www.prohealth.com)

Go to: <http://www.prohealth.com/library/showarticle.cfm?libid=19434>

### **New UAB clinical research program to combat chronic pain and fatigue**

By Katherine Shonesy

University of Alabama

December 2, 2014

UAB News

Go to: <http://www.uab.edu/news/focus-on-patient-care/item/5594-new-uab-clinical-research-program-to-combat-chronic-pain-and-fatigue>

### **The Unbreakable Laura Hillenbrand**

By Wil S. Hylton

December 18, 2014

*The New York Times*

Go to: <http://www.nytimes.com/2014/12/21/magazine/the-unbreakable-laura-hillbrand.html?mwrsm=Email&r=1>

### **University of Utah professor develops MORE intervention program for chronic pain patients**

December 6, 2014

University of Utah Health Sciences

New-Medical.Net

Go to: <http://www.news-medical.net/news/20141206/University-of-Utah-professor-develops-MORE-intervention-program-for-chronic-pain-patients.aspx>

### **Lyrica's use for treating lower back pain in fibromyalgia questioned**

By Lana Bandoim

December 12, 2014

EmaxHealth

Go to: <http://www.emaxhealth.com/12410/lyrica-s-use-treating-lower-back-pain-fibromyalgia-questioned>

### **A Randomized, Placebo-Controlled, Double-Blind, Trial of**

## **Duloxetine in the Treatment of General Fatigue in Patients with Chronic Fatigue Syndrome**

By Lesley M. Arnold

[www.prohealth.com](http://www.prohealth.com)

Go to: <http://www.prohealth.com/library/showarticle.cfm?libid=19461>

[Back to top](#)

## **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>

[Back to top](#)

## **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 Webiste**

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

[Back to top](#)

# Current Patient Studies

## New Research Studies

### 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](mailto: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>.

**[Back to top](#)**

## 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. A/V 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>.**

**[Back to top](#)**

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