



# LIGHTHOUSE

The newsletter of the  
Chronic Fatigue Syndrome &  
Fibromyalgia Support Group of  
Dallas-Fort Worth  
Volume 7, No. 4, October 2005

View the DFW Lighthouse online at:  
[www.dfwcfids.org](http://www.dfwcfids.org)

## IN THIS ISSUE

Staffing Changes .....	1
New Payment Options .....	1
Newsletter Staff Needed .....	2
Modulate Pain .....	2
New CFS Center .....	3
Update: Genes & CFS .....	3
Cheney Video News .....	4
NIH: Changes Ahead .....	4
Cheaper Drugs .....	4
NJCFS Conference .....	4
NEA Conference .....	5
Trains-NIH CFSWG .....	5
Show Me the Money .....	6
Casey Fero: Tissue/Blood Bank .....	6
FM/RA Volunteers Needed .....	7
Reverse Mental Decline .....	7
Olive Oil .....	8
Focus on Pain .....	8
Research Study for FM Pain .....	10
Media Bites .....	10
FM in Children .....	10

## SUPPORT GROUP STAFFING CHANGES

Last quarter Carla Arledge and Carvi Shamsid-Deen agreed to become our new support group leaders sharing various duties. Unfortunately, Carla is experiencing some new challenges and health issues so has resigned from this position. Carvi will continue as our Support Group Leader.

Carla has, however, generously offered to assist with member phone support as she is able. We are finding this to be a much needed service for those of us trying to cope with chronic illness, so we hope to re-establish our member phone network, which had much success in previous years during Dave Lovelace's tenure as support group leader. Look for more information about this soon.

**We Need You!** Without *you* our support group would not exist. We need your ideas, skills and participation to thrive.

If anyone understands the limitations created by chronic illness, we do! But, perhaps you still can help.

Consider your abilities, talents, and energy levels. Consider those of family and friends. What sort of small job are you able to do yourself or even share with someone else (think job-sharing here, folks!)?

Do you like to talk? Are you a good listener? Perhaps becoming a member of our phone network is perfect for you.

Let's look for some different solutions for a group of people with a very "different" illness. Contact Carvi with the skills you believe may be useful to the group. We trust that the right people will come forward at the right time.

*See page two for more support group staffing changes!*

## NEW PAYMENT OPTIONS

You can now pay for support group purchases and/or make donations with funds from a PayPal account, Debit or Credit Card (VISA, Mastercard, American Express, Discover), or eCheck (bank transfer).

The pricing reflects the extra fees these payment methods incur. Of course, payment by check (drawn on a U.S. Bank) is still acceptable! Links and a shopping cart will be

set up on our web site soon, but for those wishing to place orders now, here are the purchasing details!

**CHENEY VIDEO: NEW PURCHASE INFO**  
**Domestic U.S. Orders:** \$18 if paid by check; \$19 if paid via PayPal/Debit/Credit. Click here: <http://tinyurl.com/74z72>.

**Non U.S./Overseas Orders:** \$23 if paid by check; \$25 if paid via PayPal/Debit/Credit. Click here: <http://tinyurl.com/8awkx>.

The price includes shipping. To pay by check, make it out to "CFS/FM Support Group of DFW" and mail to:

Support Group  
6917 Vista Ridge Ct  
Fort Worth, TX 76132-4553

Video questions should be sent to [videos@dfwcfids.org](mailto:videos@dfwcfids.org). If you have questions or problems with this new payment method, email Carvi (leader@dfwcfids.org) for help.

## LJ FIDLER RESIGNS—NEWSLETTER STAFF NEEDED

Lori Fidler, who has fulfilled different jobs for this group since 1999, submitted the following letter to the members and Board of Directors on August 20, 2005.

It is with sincere pleasure that I have volunteered for this Support Group and its members the last 5 1/2 years or so producing the newsletter and working on the website. Positive changes have been made during my tenure as Managing Editor. The newsletter now has a professionally-designed masthead and layout with a circulation of 400+ and another 90 or so receiving electronic notification (saving the group a bit of money with every mailing). One of my major goals has been to maintain the standard of providing useful, quality content about a variety of CFS & FM topics in a professional manner and we have successfully met that goal.

Another of my major goals was redesigning the website to a new professional look which is well under way with current group news, several new links, and constantly changing information. The website has an astonishing average 3000+ unique visitors every month and we're already at 2500+ for this month alone. It is listed at many places on the web—personal, professional, and organizational websites. We are definitely getting the word out and are a valuable source of information to our fellow PWCs and Fibromites out there. I am pleased to have been a guiding light to the growth of both the website and newsletter.

It is with great sorrow that I must now announce my resignation, effective immediately, from the Board of Directors but also from all Support Group staff positions—most notably WebMaster and Managing Editor for the newsletter. It has been a privilege serving the group in these capacities. Since the DFW organization has successfully transferred leadership to two very capable people, Carvi Shamsid-

Deen and Carla Arledge—with Carol actively supporting them in this leadership transition—now is the best time for me to depart. The past year has been very stressful and my health has deteriorated over the past several months. I have been seeking a convenient time to exit—convenient to the organization in the sense that my exit now does not hamper the success of either the new leadership or the group.

Of course there is *always* more work to be done but I am absolutely confident that out of our many capable members, some will be able to rise to the occasion and not only enjoy taking over as webmaster and newsletter Managing Editor (or some related positions) but will help our organization mature and develop to assist even more people. I have thoroughly enjoyed working with all of you; and I expect to see you at some of the future Group meetings, when my health improves, only this time as a *civilian!*

*Good health and God Bless.*  
Lori  
(LJ Fidler)

**Editor's Note:** *We have two new volunteers: Prashant, who will become the WebMaster, and Gayathri who will assist him in managing the website. I look forward to the exciting changes they'll be integrating into the website. Thank you Prashant and Gayathri!*

*One other note, I'm helping Carvi with this issue so she isn't in a bind. That doesn't let you off the hook though! She will still need volunteers if we are to continue to have a group newsletter. Thanks again!*



## TRAIN THE BRAIN TO MODULATE PAIN

by Dennis Thompson

The power of positive thinking extends to pain, according to researchers at Wake Forest University Baptist Medical Center.

Lowering patients' expectations of pain can reduce both pain-related brain activity and how much pain they feel, says a study published in this week's issue of the Proceedings of the National Academy of Sciences.



"Positive expectations produced about a 28 percent decrease in pain ratings—equal to a shot of morphine," said lead author Dr. Tetsuo Koyama.

The study involved 10 healthy volunteers who had a heat stimulator applied to their legs while their brains were being scanned with functional magnetic resonance imaging, a technology that shows which areas of the brain are being activated.

Doctors taught the participants to expect three different levels of painful stimuli after a timed interval— short intervals for low pain and long intervals for intense pain. But the researchers scrambled up the signals, so that volunteers expecting one temperature actually received a higher or lower temperature.

People expecting moderate pain who were exposed to the most severe heat level reported about 28 percent less pain than if they had been expecting it, the researchers found. All reported diminished pain intensity for lower levels of pain.

*HealthDay News, 9/7/05; Wake Forest University, news release, Sept. 5, 2005; Copyright © 2005 ScoutNews LLC. All rights reserved. For more on the topic, visit the National Library of Medicine.*

## NEVADA CENTER FOR CFS AND CANCER

In June, the state of Nevada approved funding for a state-of-the-art clinic and research center for CFIDS and cancer at the University of Nevada-Reno. Securing the necessary funding from the state was a labor of love for CFIDS advocates Annette and Harvey Whittemore whose daughter Andrea has struggled with CFIDS for more than 17 years.

The Whittemores, along with many volunteers, worked with CFIDS clinician/researcher Dr. Daniel Peterson, many local patients and researcher-clinician Dr. Dedra Buchwald of the University of Washington and CFIDS researcher, Dr. Dharam Ablashi. Many other volunteers were also instrumental in building support among lawmakers.

Governor Kenny Guinn and state Senator William Raggio were among the early supporters of the measure as it worked its way through the state's legislative process. A long-running final session ended with passage of a funding bill providing \$10 million for the center.

The state's funding is supplemented by more than \$4 million in private funds and a commitment from the University to generously expand the investment, promising a world-class facility and faculty for the center.

The CFIDS community thanks all these wonderful supporters who collaborated to bring life to this center—now a symbol of hope for the community and soon a model for patient care and cutting-edge research in CFIDS.

Read this article in its entirety at [www.cfids.org/cfidslink/2005/out-about-S05.asp](http://www.cfids.org/cfidslink/2005/out-about-S05.asp)

## UPDATES: GENES AND CHRONIC FATIGUE SYNDROME

by Nicholas Bakalar

People who suffer from chronic fatigue syndrome sometimes have trouble persuading their doctors that they have a real disease because its symptoms are so vague and their cause so elusive.

Now a new study offers convincing evidence that patients with the syndrome, often referred to as CFS, have abnormalities in gene expression in their blood. The report appears in the August issue of *The Journal of Clinical Pathology*.

Jonathan R. Kerr, the senior author of the paper and a senior lecturer at Imperial College, London, said, "CFS patients will be pleased that such 'biological' research is progressing toward understanding their disease at the cellular and molecular level."

Using sophisticated genetic analysis techniques, the researchers compared gene expression in the blood of patients with the syndrome and that of a group of healthy controls matched for age and sex. They confirmed that the expression of 16 genes was significantly different in the patients with chronic fatigue. The authors said these gene expressions may be

important in determining the cause of the illness.

The findings are consistent with previous work showing that patients with chronic fatigue

syndrome have activated immune systems, showing increased numbers of T-cells and other germ-fighting bodies.

The genes appear to induce blood changes symptomatic of a wide variety of disorders, which may help explain why the symptoms of the syndrome are so varied.

Dr. Kerr said researchers were now ready to begin looking for treatments. "After we truly understand what is happening" on a molecular level, he said, "it will be a short leap to selecting candidate pharmacological

therapies to test in clinical trials." Source: *ImmuneSupport.com*; *New York Times*, August 2, 2005.

Related articles: "[Chronic fatigue is not all in the mind](http://www.newscientist.com/channel/health/mg18725093.700)" ([www.newscientist.com/channel/health/mg18725093.700](http://www.newscientist.com/channel/health/mg18725093.700)); "[Gene Expression in Peripheral Blood Mononuclear Cells from Patients with Chronic Fatigue Syndrome](http://www.ncbi.nlm.nih.gov/pubmed/16049284)." *J Clin Pathol*. 2005 Aug;58(8):826-32. [PMID: 16049284]; "[Chronic fatigue gene signs found](http://news.bbc.co.uk/1/hi/health/4702515.stm)" ([news.bbc.co.uk/1/hi/health/4702515.stm](http://news.bbc.co.uk/1/hi/health/4702515.stm))

### TAKE-HOME MESSAGES

- ◆ Sixteen genes were differentially expressed in patients with chronic fatigue syndrome compared with normal controls, as assessed by microarray and quantitative polymerase chain reaction
- ◆ The involvement of genes from several disparate pathways suggests a complex pathogenesis involving cell activation and abnormalities of neuronal and mitochondrial function
- ◆ These results suggest possible molecular bases for the recognised contributions of organophosphate exposure and virus infection

*J Clin Pathol*. 2005 Aug;58(8):826-32

## CHENEY JUNE 05 SEMINAR VIDEO UPDATE

The Cheney Seminar (June 18, 2005) videos are still in the process of being duplicated and mailed out. Due to the large number of orders and the time required for duplication, they are going out in batches. We received the first group of videos on August 5th and mailed them within a day or two. We received another batch on August 22th which were mailed August 24th. The orders mailed were all received on or before June 18th. More videos are being duplicated and will be mailed as soon as they are available.

For those unfamiliar with Dr. Cheney's recent work, his ongoing research confirms that CFS patients do have cardiomyopathy, specifically Diastolic Dysfunction. In this video, Dr. Cheney addresses not only this specific issue, but also presents his "big picture" view of CFS and how the cardiac/microcirculatory issue fits into it. The video is more than three hours long, includes more up-to-date information and discusses more treatment

options than "*The Heart of the Matter: Dr. Cheney on CFS & Cardiac Issues*" (the article originally released on our website, ([dfwcfids.org](http://dfwcfids.org)) April, 2005; [tinyurl.com/7vjqqj](http://tinyurl.com/7vjqqj)).

For "New Payment Options" we offer, see the article on page 1. Like all American videos, these videos are in the NTSC format; many countries use this format. However, Europe (including England) and Australia use different formats—usually PAL. *You can purchase a video, just be sure of the formatting differences and what will work for you.*

If you emailed us ([cfidsvideos@dfwcfids.org](mailto:cfidsvideos@dfwcfids.org), [videos@dfwcfids.org](mailto:videos@dfwcfids.org), or [cfidsvideos@yahoo.com](mailto:cfidsvideos@yahoo.com)) and did not receive a reply or your email bounced, we do apologize. Due to some strange server problems, about 40 emails were lost. If you have more questions, please email us again.

— Carol Sieverling

## NIH: CHANGES AHEAD

Presently, the NIH is organized by organs and body systems (e.g., National Eye Institute, the National Heart, Lung and Blood Institute, etc.). One new reform measure is to create an office to direct trans-NIH initiatives.

Working groups link administrators and researchers from different areas who handle a particular disease or families of disease. However, these groups are often voluntary and lack support, infrastructure, and funding. They suffer or dissolve when staff take new positions or leave NIH and, the outcomes they produce are uncertain and largely unmonitored.

For multi-system conditions like CFIDS that don't fit neatly into one area, participation by the diverse disciplines is crucial. This reform fosters productive partnerships to accomplish this.

Thanks to CFIDS Association of America ([www.cfids.org](http://www.cfids.org)): [www.cfids.org/cfidslink/2005/aug-ftdo.asp](http://www.cfids.org/cfidslink/2005/aug-ftdo.asp)

## DRUGS 24% CHEAPER ON CANADIAN WEBSITES

Description drugs are about 24% cheaper when bought on Canadian Internet sites than when purchased from the online sites of major U.S. pharmacy chains, new research finds.

The difference is even higher when compared to walk-in U.S. pharmacies, according to Dr. Mark Eisenberg, senior study author and

an associate professor of medicine at McGill University, Montreal.

This study compared prices on 44 common brand-name medications at 12 highly-ranked Canadian internet pharmacies and three major online U.S. chain pharmacies. Read the rest of the article at: [www.healthday.com/view.cfm?id=528047](http://www.healthday.com/view.cfm?id=528047) (9/19/05). For more information, AARP has an article on assessing Canadian pharmacies on the Internet.

Sources: Mark Eisenberg, M.D., associate professor, medicine, McGill University, Montreal; Sharon Treat, J.D., executive director, National Legislative Association on Prescription Drug Prices, Hallowell, Maine; Sept. 20, 2005, *Annals of Internal Medicine* Copyright © 2005 ScoutNews, LLC. All rights reserved.

## NJCFSA CONFERENCE

The New Jersey Chronic Fatigue Syndrome Association (NJCFSA), in association with the Monmouth Medical Center, will host a seminar, "*New Medical Findings in Chronic Fatigue Syndrome*" on November 5 at the Sheraton Conference Center in Eatontown, New Jersey.

Featured speakers will include: Dr. Paul Cheney (his latest findings in cardiology and CFS patients), Dr. Susan Levine (new research findings in the Central Nervous System of PWCs) and, Shanon McQuown, Special Education Coach (the impact of CFS on a child's education). For more information, go to [www.NJCFSA.org](http://www.NJCFSA.org).

### HAPPYNEWS.COM

Tired of depressing news stories? Visit [happynews.com](http://happynews.com). They publish only happy news. They will also email you the happy headlines daily!

## NFA CONFERENCE

Top international physicians and researchers on Fibromyalgia (FM) will be presenting the latest information on FM and chronic pain at the National Fibromyalgia Association's (NFA) concurrent patient and physician conferences scheduled for March 17-19, 2006 at the Orange County Hyatt Regency Hotel.

Sixty separate presentations and workshops for patients and physicians, and over 80 exhibitors featuring top products and services are included. Some of the featured speakers are:

- ◆ Robert Bennett, MD
- ◆ Daniel Clauw, MD
- ◆ Kim Jones, PhD
- ◆ Harvey Moldofsky, MD
- ◆ Mark J. Pellegrino, MD
- ◆ I. Jon Russell, MD
- ◆ Muhammad Yunus, MD

For more information, visit the National Fibromyalgia Association ([www.FMaware.org](http://www.FMaware.org)) or call 714.921.0150.

### DFW LIGHTHOUSE CREDITS

Published quarterly, the *DFW Lighthouse* strives to inform its members and the public about a variety of topics relating to chronic fatigue syndrome (CFS) and fibromyalgia (FM). The CFS/FM Support Group of DFW is a clearinghouse for information about CFS & FM. The Support Group does not endorse particular products or services. The ideas expressed in the *DFW Lighthouse* are strictly those of the authors or quoted individuals. The CFS/FM Support Group of DFW, and the *DFW Lighthouse* staff assume no liability for any medical treatment or other activity undertaken by readers. For medical advice, consult your healthcare provider. *Newsletter Editor: LJ Fidler (dfwlighthouse@yahoo.com). Future staff to be determined & announced later.*

*Submissions may be sent to [lighthouse@dfwcfids.org](mailto:lighthouse@dfwcfids.org). We reserve the right to edit all submissions. You must have permission before reproducing any material from the *DFW Lighthouse*. This may be obtained by emailing [lighthouse@dfwcfids.org](mailto:lighthouse@dfwcfids.org). Any address changes may be called in or emailed to Melissa Culling ([MailingList@dfwcfids.org](mailto:MailingList@dfwcfids.org)).*

Copyright © 2005 by The CFS/FM Support Group of DFW. All rights reserved. Printed in the U.S.A.

## THE TRANS-NIH WORKING GROUP ON CFS

NIH CFS research is now coordinated in the Office of Research on Women's Health (ORWH) of the Office of the Director (OD). We recognize CFS as a multisystemic illness that requires a thorough interdisciplinary approach encompassing the scientific missions of many of the NIH institutes and centers. The ORWH leadership role is exercised through the Trans NIH Working Group for Research on Chronic Fatigue Syndrome (WG), which it chairs and convenes monthly.

This new website ([orwh.od.nih.gov/cfs.html](http://orwh.od.nih.gov/cfs.html)) endeavors to provide information on the CFSWG and its programs that is helpful to researchers, health care providers, people with CFS and their families, and the general public.

### MISSION

The Trans-NIH Working Group for Research on Chronic Fatigue Syndrome mission is to:

- ◆ Stimulate and support research on CFS within the context of the missions of all Institutes, Centers and Offices.
- ◆ Collaborate and coordinate the research agendas of all Institutes, Centers and Offices to issue on a regular basis joint Program Announcements or theme-related Request for Applications to further interdisciplinary research in CFS.
- ◆ Present new knowledge to and facilitate novel theoretical approaches to CFS among NIH scientists.
- ◆ Plan and sponsor scientific symposia to foster awareness, provoke new scientific interest, and generate interdisciplinary collaboration on CFS among both the NIH and Academic medical community.

### CONCLUSIONS & FUTURE PLANS

The most important contribution the NIH can make toward advancing knowledge regarding CFS at this time is to stimulate and support high-quality research throughout its programs on the causes, consequences and treatment of CFS and related diseases.

To this end, the CFS Working Group is planning three new scientific workshops to address:

- ◆ Study of CFS across the lifespan
- ◆ Treatment Approaches to CFS
- ◆ Issues in Doctor-Patient Relationships in the clinical interview to explain the stigma felt by many multisystemic disease sufferers to impact their medical care.

By continuing and expanding efforts to solicit and fund new scientific initiatives as well as attract new researchers to the field, the NIH expects to increase the number of opportunities available to direct increased resources to CFS research.

It is also expected that by cooperating in planning these interdisciplinary initiatives, the many ICs working on CFS will increase cooperation in encouraging multidisciplinary and interdisciplinary CFS research as well as cofunding such research.

### DONATIONS

Once again folks, you've been busy and we thank you for your efforts! Don't forget iGive.com and Tom Thumb! Our totals this quarter are:  
Kroger ..... \$121.50  
For questions or information about the shopping donations program, contact Carol Sieverling ([treasurer@dfwcfids.org](mailto:treasurer@dfwcfids.org)). If you would like to make a donation to our group, contact Carvi, our Support Group Leader ([leader@dfwcfids.org](mailto:leader@dfwcfids.org)).

THANK YOU FOR YOUR FAITHFUL SUPPORT!

## SHOW ME THE MONEY: ACTION ALERT—NIH

by Pat Fero, Wisconsin CFS Association

With careful research, I prepared and presented a report in March 2004 to the Chronic Fatigue Syndrome Advisory Committee. I asked for an investigation.

With 6 million dollars a year, not much more than in 1995, funding levels have declined. I do not have a problem with that. NIH never has enough money to go around. What I do have a problem with is that *millions of dollars appear to be spent in the name of CFS, but not on CFS-specific studies.*

I continued my research through 2004 to look at the grant review panels and keep track of grants funded. I am still left with this question:

*Where is the CFS money?*

Therefore, I prepared another report ([www.wicfs-me.org/whats\\_new.htm#action%20alert](http://www.wicfs-me.org/whats_new.htm#action%20alert)). It contains a cover letter and a list of appendices with pages of lists. The point is to show that something is wrong with how CFS grants are funded. It is in the numbers and in the lists.

What is to be done? Who holds the NIH personal accountable to the estimated 800,000 people in the US who have CFS? Despite feeling horrid, despite obstacles, we all have to take this information to our senators and our congress people. This is our backyard to clean up and no one will do it for us.

I am pleading with you to take action. Please open the ACTION ALERT file and print; the web addendum file includes more supporting documents. Speak to the health aide at the LOCAL office of your congressperson and senator. Briefly explain the prob-

lem and that you have a one-page letter plus lists of supporting information. Our ultimate goal is to ask that the 1999-2000 Government Accounting Office (GAO) investigation of NIH be reopened. Staffers get hundreds of calls daily, so keep it short. They will tell you where to send the report. Often, mail sent to local offices is more easily forwarded than that sent to Washington DC offices.

If only 10 people in each state went to their representatives with the report and the GAO request, it would make a huge difference. Might you be the person that tips the scales? After you've done this, please e-mail Pat Fero ([bp.fero@verizon.net](mailto:bp.fero@verizon.net)). Put your state in the subject line. Give the name of the senator or congressperson who received the information. If we do not have better research, we can never change the CFS mythology. With continued bias and bigotry, people suffer beyond the illness. Right now, we are not asking for a cure or better treatments. We are just asking for a fair deal.

Hundreds of CFS researchers care and we need to help clear a path so they can continue their work.

Last of all, we are asking others to do right by us and by our children. I lost my son Casey July 4th. He was 23 with ME-CFS illness onset at age nine. Casey's very peaceful death was directly or indirectly related to this illness. As a mother, I do not have to be scientific and no one dare make me prove what I know in my heart is true after living with this boy ill for 14 years.

*Thanks to Co-Cure.org and the Wisconsin CFS Association for this information. You can also find a link to the cover letter and pdf files Pat references in the left column of our archives.*

## CASEY FERRO: ME/CFS TISSUE & BLOOD BANK

On July 4, 2005, at the age of 23, Casey Fero died in his sleep. He died of unknown causes far too young. Casey was diagnosed with CFS at age 9 and again at age 15. He was plagued with headaches, and a major sleep disorder among a list of daily symptoms. But Casey persevered even though he knew early on that medical help was unavailable. He was met with disbelief both in school and at the doctor's office.

Sound medical research is the key to understanding the cause of these disorders and to developing treatments. Many illnesses were poorly understood prior to the creation of tissue and blood banks. Precious gifts of tissue and blood benefit all. As a lasting tribute to Casey, the first universal access blood and tissue bank for ME-CFS patients will be created.

A universal-access specimen bank means that any scientist can ask for samples provided their study meets specific guidelines. The Institute for Viral Pathogenesis, ([www.ivpresearch.org](http://www.ivpresearch.org)), a Medical Diagnostic Laboratory in Milwaukee, will house the freezer. Government-regulated procedures are in place to care for donations.

The cost to buy a storage freezer at the facility is \$10,000. Tax-deductible contributions (*through the Wisconsin CFS Association; Federal ID# 39-1614649*) may be made online ([www.wicfs-me.org](http://www.wicfs-me.org)) or via check to (*Specify Casey's Fund*): Wisconsin CFS Association; 747 Lois Dr.; Sun Prairie, WI 53590. These contributions are dedicated to Casey and will not be used for any other purpose.

Contact: Pat Fero ([bp.fero@verizon.net](mailto:bp.fero@verizon.net))  
Editor's Note: The Casey Foundation, right now, can **ONLY** take money.



## FM &/OR RA STUDY VOLUNTEERS NEEDED!

**A** University of New Mexico graduate student (Family Studies) needs your help! Her doctoral research is on mothers with fibromyalgia and/or rheumatoid arthritis and the effects on their children. She needs mothers aged 25-57 who have a child (ages 11-17) living with them and have been diagnosed with fibromyalgia and/or rheumatoid arthritis. You and your child each will be asked to complete a 30-minute questionnaires sent to you by U.S. mail.

If you would like to participate or learn more about the study, contact researcher Marie M. Duryea ([mduryea@unm.edu](mailto:mduryea@unm.edu)).

**CFS/FM SUPPORT GROUP OF DFW  
STAFF INFORMATION**  
[WWW.DFWCFIDS.ORG](http://WWW.DFWCFIDS.ORG)  
817.303.4851

### Support Group Leader

Carvi Shamsid-Deen ..... [carvi@dfwcfids.org](mailto:carvi@dfwcfids.org)

### eList Managers

Mary Martini ..... [mlmbirdwatcher@yahoo.com](mailto:mlmbirdwatcher@yahoo.com)  
Carol Sieverling ..... [carol@dfwcfids.org](mailto:carol@dfwcfids.org)  
Sheri (chat) ..... [sherimmm@yahoo.com](mailto:sherimmm@yahoo.com)  
Tammy (chat) ..... [xgoode@yahoo.com](mailto:xgoode@yahoo.com)  
*elists: CFS-FM-DFW, CFS-FM-DFW-chat & DFW\_Newsletter at www.yahogroups.com*

### Gentle R&R Coordinator

Gentle R&R ..... [GentleRandR@dfwcfids.org](mailto:GentleRandR@dfwcfids.org)

### Mailing List Manager

Melissa ..... [MailingList@dfwcfids.org](mailto:MailingList@dfwcfids.org)

### Media (A/V) Manager

Jake ..... [videos@dfwcfids.org](mailto:videos@dfwcfids.org)

### Referral Lists Manager

Deborah Hart ..... [ReferralList@dfwcfids.org](mailto:ReferralList@dfwcfids.org)

### Webmaster

Prashant ..... [Prashant@dfwcfids.org](mailto:Prashant@dfwcfids.org)

### Board of Directors

President ..... Carvi Shamsid-Deen  
Vice-President & Secretary .....  
Jennifer Fix, R.Ph. .... [swingrx@aol.com](mailto:swingrx@aol.com)  
Treasurer ..... Carol Sieverling  
Dave Lovelace ..... [georgiedave@charter.net](mailto:georgiedave@charter.net)  
Larry Sharp, D.O. .... 817.924.1010

Operating Fund: \$1,137.69

## REPORT SHOWS MENTAL DECLINES CAN BE REVERSED

**A**s we get beyond retirement age, most of us will not be as mentally sharp as we once were. But a researcher at the University of Alberta says most people have the ability to reverse the mental declines that come with aging.

"Can we reverse mental declines? Well, for most of us, the answer is yes, and I think that is definitely exciting and encouraging news," said Dr. Dennis Foth, a professor in the University of Alberta Faculty of Extension and the academic director of the U of A's Certificate in Adult and Continuing Education.

Foth and his research colleague, Dr. Gordon Thompson of the University of Saskatchewan, also found in their literature review that mental declines related to aging are not universal (they affect some more than others), and they are not pervasive (the declines normally affect different parts of our cognitive capacities to varying degrees).

Foth said mental declines are pathological for about 10 per cent of the general population over the age of 65, and not much can be done at this time to overcome the debilitating cognitive effects of diseases that affect the brain, such as Alzheimer's disease. But for the other 90 per cent of the population, cognitive decline need not be inevitable.

"A lifetime of good mental habits pays off," Foth said. "People who are curious at a young age are more likely to be mentally active and stay active as they age. And we found it is never too late to start. With a little effort, even people in their 70s and 80s can see dramatic improvements in their cognitive skills."



There are many different types of classes and mental exercises that people can do to keep their minds vibrant, Foth said, but "the trick to getting more people to maintain or even improve their cognitive abilities is "ecological validity".



Ecologically-valid activities are those that people do on regular basis as part of their daily lives, said Foth, whose paper with Thompson is published this month in *Educational Gerontology*.

Examples of "ecologically-valid" activities that can improve mental capacity include reading, traveling, memorizing poetry, playing card games, doing crossword puzzles, learning how to play a musical instrument, taking continuing education courses and surfing the Web.

Foth and his colleagues are beginning to study these activities to determine which ones improve which cognitive skills. He believes this research can lead to the development of learning programs and activities that can isolate mental declines and reverse them. He added that attitude can play an important role in maintaining cognitive skills throughout life.

"People often describe their memory skills as being far worse than they actually are, and this type of attitude can start a vicious cycle," Foth said. "These people won't enroll in a class that might be beneficial to them because they believe they wouldn't be good at it. We have to protect against that."

University of Alberta; Dr. Dennis Foth (780.492.5865; [dennis.foth@ualberta.ca](mailto:dennis.foth@ualberta.ca)). [ImmuneSupport.com](http://www.immunesupport.com), 09-16-2005 (<http://www.immunesupport.com/library/showarticle.cfm/ID/6717>)

## OLIVE OIL: NATURAL ANTI-INFLAMMATORY AGENT

**A** naturally-occurring chemical found in extra-virgin olive oils is a non-steroidal anti-inflammatory agent, report scientists from the Monell Chemical Senses Center and collaborators at the University of Pennsylvania, The University of the Sciences in Philadelphia, and Firmenich, Inc.

Named oleocanthal by the researchers, the compound inhibits activity of cyclooxygenase (COX) enzymes, a pharmacological action shared by ibuprofen.

This finding is significant because inflammation increasingly is believed to play a key role in a variety of chronic diseases. "Some of the health-related effects of the Mediterranean diet may be due to the natural anti-COX activity of oleocanthal from premium olive oils," observes Monell biologist Gary Beauchamp, PhD. (Read the findings as described in the September 1 issue of *Nature*).

The scientists were led to the discovery by the serendipitous observation that fresh extra-virgin olive oil irritates the back of the throat in a unique and unusual manner. "I had considerable experience swallowing and being stung in the throat by ibuprofen from previous studies on its sensory properties," explains Beauchamp. "So when I tasted newly-pressed olive oil while attending a meeting on molecular gastronomy in Sicily, I was startled to notice that the throat sensations were virtually identical."

Taking their lead from the cues provided by olive oil's throaty bite, the scientists systematically evaluated the sensory properties of an unnamed chemical compound thought to be responsible for the throat irritating property of premium olive oils. Results confirmed that the irritating intensity of a

given extra-virgin olive oil was directly related to how much of the chemical it contained.

To rule out the possibility that any other compound was involved, they created a synthetic form identical in all respects to that found naturally in olive oil, and showed that it produced exactly the same throat irritation. Co-author Amos Smith, PhD, explains, "Only by de novo synthesis could we be absolutely certain that the active ingredient was oleocanthal."

The sensory similarities between oleocanthal and ibuprofen led scientists at Monell and the University of the Sciences to investigate potential common pharmacological properties. Studies revealed that, like ibuprofen, oleocanthal inhibits activity of COX-1 and COX-2 enzymes. Because inhibition of COX activity underlies the anti-inflammatory actions of ibuprofen and other non-steroidal anti-inflammatory drugs (NSAIDs), the new findings suggest oleocanthal is a natural anti-inflammatory agent.



Monell sensory scientist Paul Breslin, PhD, who directed the research with Beauchamp remarks, "The Mediterranean diet, of which olive oil is a central component, has long been associated with numerous health benefits, including decreased risk of stroke, heart disease, breast cancer, lung cancer, and some dementias. Similar benefits are associated with certain NSAIDs, such as aspirin and ibuprofen. Now that we know of oleocanthal's anti-inflammatory properties, it seems plausible that oleocanthal plays a causal role in the health benefits associated with diets where olive oil is the principal source of fat."

### FOCUS ON PAIN

**F**ive to 10 chronic pain patients (need not have FM and/or CFS) are needed to review the second prototype of the Pain Self-Management Program. It takes 2–2 ½ hours; reviewers are paid \$50. To determine eligibility, complete the profile of chronic pain at [www.PainSurvey2.speedsurvey.com](http://www.PainSurvey2.speedsurvey.com). The survey takes about seven minutes to complete. If eligible, you will receive a copy of the Pain Self-Management Program CD-ROM and instructions in the mail.

Thanks to the Livonia CFS Support Group and the National Fibromyalgia Association.

Beauchamp said future research will aim to identify how oleocanthal inhibits COX enzymes and how this relates to throat sting. According to Breslin, "This study is the first to make the case for pharmacological activity based on irritation and furthers the idea originally proposed decades ago by Fischer that a compound's orosensory qualities might reflect its pharmacological potency."

*The Monell Chemical Senses Center ([www.monell.org](http://www.monell.org)) is a nonprofit research institute based in Philadelphia, Pennsylvania. Using a multi-disciplinary approach, they collaborate in: sensation and perception, neuroscience and molecular biology, environmental and occupational health, nutrition and appetite, health and well-being, and chemical ecology and communication.*

Thanks to ProHealth: [prohealth.com/library/showarticle.cfm/ID/2629](http://prohealth.com/library/showarticle.cfm/ID/2629); 09-12-2005.

CITATION: Beauchamp, G.K., Keast, R.S.J., Morel, D., Lin, J., Pika, J., Han, Q., Lee, C-H, Smith, A.B. III, Breslin, P.A.S. Ibuprofen-like activity in extra-virgin olive oil. *Nature*, 2005, 437, 45-6.

## GENTLE R & R SESSIONS

### TUES., OCT. 18 CHAIR SESSION

6:00—6:45 p.m.

Stretch, breath, and relax while seated in a chair. Bring a strap and a bottle of water. If your feet don't reach the ground when sitting in a chair, bring a shoe box or yoga block to rest your feet on.

*Location: West II Room, Edwards Cancer Center. RSVP: GentleRandR@dfwcfids.org.*

### TUES., NOV. 15 BREATH AWARENESS—CHAIR SESSION

6:00—6:35 p.m.

Prepare for the holidays! Explore your breathing capacity! Practice breathing techniques which not only increase oxygenation to the body and mind but promote relaxation. Bring a bottle of water. If your feet don't reach the ground when sitting in a chair, bring a shoe box or yoga block to rest your feet on.

*NOTE: This is only a 30-minute session. Please be on time! To maintain quiet, the East conference room door will be closed during the session. It will re-open at 6:45 for the regular support group meeting.*

*Location: East Room, Edwards Cancer Center. RSVP: GentleRandR@dfwcfids.org.*

### THU., DEC. 8 HOLIDAY EXTRA STRESS BUSTER/FLOOR SESSION-RESTORATIVE YOGA

7:00—9:00 p.m.

Take the edge off during the holidays! Bring your mats, neck pillows, cushions, & water. The postures will be done on the floor. These postures are very gentle & designed to open up breathing pathways and promote relaxation to the entire body and mind.

*Location: East Room, Edwards Cancer Center. RSVP: GentleRandR@dfwcfids.org.*

**Please Be Aware!** Many members are quite chemically sensitive. Out of consideration, please try to avoid the most common offenders: fragrances, perfumes, smoke, dry cleaning fluids, household products &/or chemicals, or clothes exposed to these.

## UPCOMING MEETINGS

### TUES., OCT. 18 HELPFUL SOLUTIONS FOR THE HOLIDAYS

7:00—9:00 p.m.

#### Carvi Shamsid-Deen, Facilitator

Holidays are a rough time for all. Come share tips that get you through the holidays with less stress. Topics will include shopping, holiday cards & gift packaging, parties & family gatherings, food selection and preparation. Don't forget to bring your quick and easy recipes!

If you are able, write down your tips and bring 25 or so copies. It really helps everyone remember what was said in these fast-paced meetings. If you are not able to bring your own copies, email your tips to leader@dfwcfids.org by October 11th and we'll print tip sheets for distribution at the meeting.

*Location: West I Room, Edwards Cancer Center*

### TUES., NOV. 15 INDOOR AIR QUALITY

7:00—9:00 p.m.

#### Steven Bush, Certified Indoor Environmentalist

Steven Bush of RIA Consultants has eight+ years experience in residential indoor air quality. He is a member of both the Texas Indoor Air Quality Association and the National Indoor Air Quality Association.

Steven will discuss the causes of poor indoor air quality, including sources, things we do to create it, and, home design and construction. He will also provide solutions and ideas to prevent and correct poor indoor air.

Steven and the RIA Consultants staff have consulted in over 2,000 homes in the Metroplex. They are a State of Texas provider that trains and certifies individuals and companies for Mold Assessment and Remediation licensing as required by the State of Texas.

*Location: East Room, Edwards Cancer Center*

## DECEMBER NO REGULAR SUPPORT GROUP MEETING

YEAR 2006

### SAT., JAN. 21, 2006 MOVIE MATINEE: "I REMEMBER ME"

2:00—4:30 p.m. (date and time tentative)

Introducing our first movie matinee! "I Remember Me," a film by Kim Snyder, is the first full-length documentary to explore the controversial and mysterious history of CFS. Kim, battling the illness herself, went on a four-year journey in search of answers. She interweaves her own story with those of others facing the same challenges. More than an account of an epidemic unfolding, "I Remember Me" speaks to universal themes of loss, human perseverance, and our difficulties in grappling with uncertainty.

This movie is not just for those with CFIDS, FM, or other chronic illnesses, but also for family and friends. So, bring them along!

*Be aware that the movie may trigger memories and strong emotions for those viewing it. It may or may not be appropriate for children—you decide!*

*Location: East Room, Edwards Cancer Center*

## RESEARCH STUDY FOR FIBROMYALGIA PAIN

**D**o you experience aches and body pains, muscle stiffness, and extreme fatigue? If you are at least 18 years old and experience symptoms of fibromyalgia, you may qualify to participate in a clinical research study. Study benefits include investigational study medication, and study-related exams (i.e., physical exams, lab test) at no cost.

Update from Dr. Sharp, "We still need about 15 more patients. CFS is not a rule-out but the medicine works for pain and sleep disturbances. Anyone interested should contact Dora at 817.907.6084."  
Dr. Larry J. Sharp,  
DFW Wellness

## FM IN CHILDREN

By Stephanie Rochon, News 6 Network

**Y**ou felt like you had no energy. I felt kind of depressed because I didn't know what was going on. She didn't know what was going on, but Ashleigh Zinski and her mother knew something was wrong. Susan Zinski says Ashleigh had extreme nausea, chronic fatigue, sore aching muscles, and severe headaches. The bright, athletic then 13 year-old was sluggish and in pain. She dropped off the basketball team and her grades were dropping. Her mother took her to four specialists without any luck. Ashleigh says, I was angry because I knew something was wrong, but they wouldn't do anything about it.

Read the rest of the story at: <http://tinyurl.com/834jk>. Thanks to Co.Cure.org.



## MEDIA NOTES

**D**orothy Wall of the San Francisco Gate (sfgate.com) wrote an excellent article, "From Skepticism to Science: After 20 years, chronic fatigue syndrome may finally be getting some respect and cutting-edge science" on June 5, 2005. Read the article at [tinyurl.com/b32br](http://tinyurl.com/b32br).

Judy Forman of The Boston Globe wrote, "Research Clarifies True Chronic Fatigue," September 8, 2005 ([www.iht.com/articles/2005/09/07/news/snfat.php](http://www.iht.com/articles/2005/09/07/news/snfat.php)).

On September 30, "Sit and Be Fit," ([www.sitandbefit.org](http://www.sitandbefit.org)) the award-winning television series, aired a segment on fibromyalgia in Dallas-Fort Worth, TX and Spokane, WA featuring NFA president Lynne Matallana as the special guest.

RETURN SERVICE REQUESTED

P.O. Box 433  
Grapevine, Texas 76099-0433  
817.303.4851

The Newsletter of the Chronic Fatigue Syndrome & Fibromyalgia Support Group of Dallas-Fort Worth  
[www.dfwcfsids.org](http://www.dfwcfsids.org)

**LIGHTHOUSE**

NonProfit Org  
U.S. Postage Paid  
Eulless, Tx  
Permit No. 19

# DFW LIGHTHOUSE: OCTOBER 2005 TABLE OF CONTENTS

NEW PAYMENT OPTIONS .....	1
SUPPORT GROUP STAFFING CHANGES .....	1
LJ FIDLER RESIGNS—NEWSLETTER STAFF NEEDED .....	2
TRAIN THE BRAIN TO MODULATE PAIN .....	2
NEVADA CENTER FOR CFS AND CANCER .....	3
UPDATES: GENES AND CHRONIC FATIGUE SYNDROME .....	3
CHENEY JUNE 05 SEMINAR VIDEO UPDATE .....	4
DRUGS 24% CHEAPER ON CANADIAN WEBSITES .....	4
NIH: CHANGES AHEAD .....	4
NJCFSA CONFERENCE .....	4
NFA CONFERENCE .....	5
THE TRANS-NIH WORKING GROUP ON CFS .....	5
SHOW ME THE MONEY: ACTION ALERT—NIH .....	6
CASEY FERO: ME/CFS TISSUE & BLOOD BANK .....	6
FM &/OR RA STUDY VOLUNTEERS NEEDED! .....	7
REPORT SHOWS MENTAL DECLINES CAN BE REVERSED .....	7
OLIVE OIL: NATURAL ANTI-INFLAMMATORY AGENT .....	8
FOCUS ON PAIN .....	8
GENTLE R & R SESSIONS .....	9
UPCOMING MEETINGS .....	9
YEAR 2006 .....	9
RESEARCH STUDY FOR FIBROMYALGIA PAIN .....	10
FM IN CHILDREN .....	10
MEDIA BITES .....	10