

# January 2009 Newsletter

The Northern Virginia (NOVA) CFS/ME, FM/ FMS and OI Support Group with CFSsupport e-mail is an informal encouraging and educational discussion group with meetings, email outreach and a website. We welcome those with Chronic Fatigue Syndrome / ME, FMS / Fibromyalgia and similar disorders -- IBS, MCS, & the Orthostatic Intolerances (OI): NMH, POTS and MVPS / dysautonomia. We are peer led by volunteers who respect and talk fluently about the symptoms and issues surrounding these conditions. Please join us and share in our discussions, speaker events, and low volume e-mail list. See website for:

- lists of practitioners, health care & legal
- books, videos, articles, links
- more organizations for CFS/FM and other
- clinical trial info, research information
- coping tips, treatment articles
- media coverage, conference information
- detailed newsletters, and more.

*Chronic fatigue syndrome (CFS/CFIDS) has long-lasting, multiple effects including severe exhaustion, widespread muscle weakness and pain, disabling problems with memory and concentration, and persistent flu-like symptoms.*

*Fibromyalgia Syndrome (FMS/ FM) is a complex, chronic state known for its widespread pain and fatigue, with a variety of other symptoms very similar to the ones for CFS and OI. The name derives from "fibro" meaning fibrous tissues (such as tendons and ligaments), "my" meaning muscles, and "algia" meaning pain.*

*Dysautonomia means dysfunction of the ANS (autonomic nervous system) and involuntary functions such as blood pressure, respiration, heart rate, and digestion. Symptoms include neck, back, and other muscular aches, tension or twitching; lightheadedness; irritable bowel; chest pain; panic; anxiety; fatigue; migraines; weakness; alcohol and heat intolerances; pallor or redness of extremities; numbness/tingling; depression/mood swings loss of concentration; hypersensitive startle reflex; memory problems or foggy thinking; swelling of extremities, feelings of electrical current; skin problems; sleep difficulties; allergies; feeling hot or cold-unrelated to external temperature; visual disturbances and more.*

## MEETINGS

*Usually, 3rd Saturdays from 2 – 4 pm*

**Sully Governmental Center  
James McDonnell Room  
4900 Stonecroft Blvd, Chantilly VA 22003**

Exceptions noted below. Events are free, donations accepted. Close parking, no stairs. Same bldg as Sully Police Station.S. of Dulles Airport, between Routes 50 and 66, just west of Route 28 off Westfields Blvd.

## 2009 NOVA Schedule

**Jan 17 - Medical Qigong**

**Matt Hayat, PhD, NMQ:**

Feb 28 - discussion meeting (4th Saturday-2 pm)

**Mar 21 - Peter Rowe, MD, Johns Hopkins,**

**"Update on Orthostatic Intolerance in CFS (& FM)"**

Apr 18 - discussion meeting

**Apr 25 - "Chronic Fatigue Syndrome (CFS):**

**Is Oxygen the Problem & Why?**

**A 4-Part Treatment Protocol"**

**Paul Cheney, MD/PhD**

Fairfax Government Center

Board Auditorium

12000 Government Center Parkway

Fairfax, VA 22035

May 16 - discussion meeting

Jun 20

Jul 18 (10 am)

Aug 15

Sep 19 (10 am)

Oct 17

Nov 21

Dec 19 - Social / POT(S) Luck Late Lunch

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*Please refrain from wearing scented products.*

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**DIRECTIONS to Sully Governmental Center:**

From Route 28, exit West onto Westfields Blvd. Make first Right which is at the first light onto Stonecroft. Make *immediate* left into parking lot.

## NOVA CFS/ME, FM, OI SUPPORT GROUP

### Contact information

Elly Brosius (703) 968-9818  
Toni Marshall (410) 647-7578  
Email: CFSupport-owner@yahoogroups.com  
Website: www.geocities.com/cfsnova  
To sign up for NOVA's CFSupport e-mail:  
http://groups.yahoo.com/group/cfsupport or  
CFSupport-subscribe@yahoogroups.com

### NOVA GEOCITIES WEBSITE 101

Our Geocities.com/cfsnova site continues to grow and be updated to be more easy to navigate, especially if you are having an off day. To see the "How to Use this Site" page, click on the DC picture. It tells about the drop down menu, the site map and searching. For article links for newly diagnosed, click on the Blue Ribbon symbol of awareness. Check the Events page for speaker updates and nearby groups.

### ELLY'S GRATITUDE GROUP (EGG)

#### Teleconferences

for those with CFS/FM/OI with  
EGGdish - The Yahoo Group for EGG

*A mind-body-spirit discussion group for those looking to practice using attitude and other mind/spirit influences to heal and share in the safety of others who "get" CFS / FM / OI / chronic illness. We use gratitude to uplift ourselves in times of great physical challenges, to add balance to what is overwhelmingly difficult.* For phone number and code and dates and times, join CFSupport or EGGdish Email list or call group contacts Elly or Toni. Callers are responsible for their own long distance charges. No other fees. See also www.geocities.com/cfsnova/egg.html

### NOVA MVPS / Dysautonomia & OI GROUP

2nd Tues, Noon - 2 pm. Meets by teleconference!!  
For number, code, call (703) 968-9818, email mvps-d\_oi\_nova@yahoogroups.com or see www.geocities.com/cfsnova/mvpsoi.html

### MORE WASHINGTON DC AREA SUPPORT

PainConnection.org (301) 309-2444  
Loudoun CFS/FM Seminars (703) 968-9818  
Loudoun Daytime Group (703) 244-4941  
Bethesda FM/CFS Group (301) 718-9326  
Woodbridge FM Group (703) 221-4972  
Check our "Other Groups" web page for more.

## AWARENESS DAY 2008 Seminar Recording

For May 12, CFS/FM Awareness Day, NOVA facilitator Elly Brosius presented a teleconference with chronic neurological illness expert and Eastern Medical Practitioner Jonathan Gilbert. Listen online or by telephone, or write us for the MP3 file. WhenPushingStopsWorking.com/Audio.html  
Call in: (641) 715-3413, code 312812.

## NATIONAL FMS & CFS ORGANIZATIONS

**CFIDS Assoc. of America** (704) 365-2343  
*cfids.org*  
**International Association for CFS/ME**  
*iacfsme.org*  
**Fibromyalgia Network** (800) 853-2929  
*fmmnetnews.com*  
**National FM Association** (714) 921-0150  
*fmaware.org*  
**National FM Partnership** (866) 725-4404  
*fmpartnership.org*  
**FM Coalition International** (913) 384-4673  
*fibrocoalition.org*  
**ProHealth.com** (800) 366-6056

## QUOTES ABOUT SUPPORT GROUPS

"An understanding approach by the physician and the patient's participation in a well-run support group may have considerable therapeutic benefit."

- David A. Nye, M.D.

"One thing he [Dr. Frank Scifo, family practitioner in private practice in Stratford, CT] recommends for most patients is attending a support group. Since it took a long time for some of these patients to receive validation from the medical community, being in a group of people who support them and acknowledge their illness can be immensely helpful, Scifo said."  
"Too tired: CDC Gives Credence to Diagnosis of CFS" Connecticut Post - September 20, 2006

"Support groups help a lot with understanding the disease, coping with the disease, getting the best out of life, breaking down barriers and overcoming hurdles."

- Dr. Charlene Hafer-Macko, associate professor of Neurology and Medical Director of University of Maryland's Myasthenia Gravis Center.  
Loudoun CFS and FM/Chronic Pain Seminar Series