



CFSUPPORT x 10!

Speakers, Emails & Calls

Oh My!! We're not just Northern VA (NOVA) Anymore

NOVA CFSupport Group
 In Person, E-mail, Web, Teleconferences
cfsupport-owner@yahoo.com
groups.yahoo.com/group/CFSupport



www.geocities.com/cfsnova
 Elly Brosius (703) 968-9818
 Toni Marshall (410) 647-7578
 2009 Meetings - 4900 Stonecroft Blvd
 Sully Government Center, Chantilly VA
 2-4 pm, 3rd Saturdays, except
 2/28 (4th Sat) & 10am 7/18, 9/19

The NOVA support group email list of encouragement, information, and reminders turned ten on February 12, 2009.

Though we've subscribers all over the world, we wanted to send something special by snail mail for the mid-atlantic region.

With help from The CFIDS Association, due to our hosting two internationally recognized Chronic Fatigue Syndrome (CFS)

experts, Peter Rowe, MD, & Paul Cheney, MD/PhD in Chantilly and Fairfax, we're reaching out again.

If you haven't heard from us since the last mailing in 2005, our CFSnova website was expanded and includes practitioner listings. (Please see the "About this List.")

Until the next meeting, phone, or cyberspace encounter, ...

Elly Brosius and Toni Marshall

Ten Years of Email

It is no piece of cake to have mysterious syndromes. Most of us avoid the wheat, dairy, and sugar in cake or feel worse. We're celebrating with a photo and zero calories!

Ten years of email with a significant web presence, 16+ years of in person meetings and speakers, we've had to get cooking on creative ways to cope or be bored to tears.

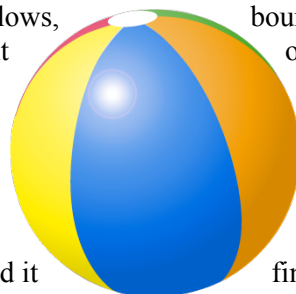
We still offer speaker or share meetings but we change the locations, we've added a mind-body teleconference conference, a POTS and PANS phone group, an email list for gratitude journaling, and indulgent times with flourless chocolate domes.

Join us in CF Support by emailing cfsupport-subscribe@yahoo.com and then registering.



LIFE AS A BEACHBALL - HOW DO YOU ROLL?

A perfectly inflated beach ball. It absorbs blows, flexes, springs forth, flying away to the next person. It has flexibility and resiliency. It returns to its original shape. If we roll it across a mostly smooth floor, it might bump a little off pebbles or fuzzies, but it would stay on its intended course. Picture two ways to stress a beach ball. Overinflated it



bounces more, off the walls with excitement, tiny obstacles send it careening off course. It could pop, deflate needing to be patched up. An under inflated ball, from say a slow leak, thuds, gets stuck on fuzzies, stops rolling. It loses its shape, its identity. These remind us of the ways a person feels stress. May we all find ways to our original shape and bounce.



NOVA'S TELECONFERENCING: INFO, SUPPORT FOR, COPING WITH PAIN, FATIGUE, + + + +



Dial-In Number
(218) 339-2699
Code
5 6 8 3 9 4 #

The Calls of POTS & PANS

In Sept 2008, the Mitral Valve Prolapse Syndrome (MVPS/D) and OI meetings became teleconferences, more generally about all the nervous system symptoms. We include more CFS and FM since dysAutonomia symptoms often overlap. Thinking about body experiences as Problems with the Autonomic Nervous System (PANS) and poor circulation gives us many strategies for lessening the severity and frequency of symptoms, e.g. managing electrolyte intake (including salt) while balancing with liquid intake. To which symptoms do we refer? All of them!

Especially the super sensitivities, too hot or cold, fatigue, pain, and shakiness, postural tachycardia, neurally mediated hypotension, low blood volume, startle reflex, lightheadedness.
Calls are the 2nd Tuesday of every month at 12 pm Eastern.

The EGG Calls for Gratitude

In late 2005, NOVA's new mind-body-attitude sister group of gratitude began experimenting with teleconferencing as another way of connecting, supporting each other and ourselves, breaking up the isolation.

EGG is about practicing an attitude of gratitude, together, while still acknowledging our awful or difficult health and other challenges, whether they be from CFS, FMS, IBS, IC, MCS, Chronic Lyme, vulvodynia, We also help each other rephrase our language for a more constructive spin. We practice appreciation for saving energy, for creativity about old situations, to accelerate any possible healing.

EGG Calls are monthly and only set about a month in advance. **Next call is March 30, 3:30 pm, Eastern.**

MORE DC / BALTIMORE AREA CHRONIC FATIGUE SYNDROME & FIBROMYALGIA GROUPS

Loudoun CFS & FM / Chronic Pain Seminar Group

CFSsupport-owner@yahoogroups.com
 Leesburg, VA. Elly (703) 968-9818

Bethesda FM/CFS Support Group

Andrea aflagiello315@yahoo.com
 Marielle (301) 718-9326

Daytime FM / CFS Support Group Walk & Chat Group Sterling, VA

Patti laycfam@hotmail.com
 Adriana aekupe@aim.com
 Rowena beattyrk@wans.net

Baltimore CFIDS Network

cfidsbaltmd.tripod.com
 St Agnes Hospital: (410) 368-3330

WoodbridgeFibromyalgia

groups.yahoo.com/group/woodbridgefibromyalgia

Compass Support Timonium, MD

Therese compasssupport@comcast.net



(410) 647-7578

TONI MARSHALL - MARYLAND BAY AREA PHONE / EMAIL CONTACT

Our CFSupport Co-moderator Toni Marshall continues to uplift people with conditions. She is active and helpful in yahoo groups EGGdish and CFAlliance. In 2008, Toni won an NFA International Leaders Against Pain Conference Scholarship. She continues to do media interviews, email individuals, and offer phone support. Thanks, Toni. Way to go!



Peter Rowe, MD - March 21 Chantilly VA



Peter Rowe is the Sunshine Natural Wellbeing Foundation Professor of Chronic Fatigue and Related Disorders, Dept. of Pediatrics, Johns Hopkins University School of Medicine. Director, Chronic Fatigue Clinic, Johns Hopkins Children's Center.

Dr. Rowe will describe the links between disturbances in the control of blood pressure and heart rate in those with CFS (and FM and similar syndromes). He will discuss practical aspects of managing symptoms caused by the circulatory problems, by dysautonomia (POTS, NMH, MVPS/D, OI).

Dr. Rowe has conducted landmark research on CFS and published medical and practical guides. He is liked immensely, helpful, and respected. See our page on him at geocities.com/cfsnova/sp-Rowe.html

Update on OI in CFS
(Orthostatic Intolerance)

**Sully Government Center
Rooms 1 and 2**

**4900 Stonecroft Blvd
Chantilly VA 20151**

2 - 4 p.m.

Saturday March 21, 2009

Free

Please refrain from wearing scented products. Bring your comforts.

Paul Cheney, MD/PhD April 25 Fairfax VA



Paul Cheney, known more recently for his work with CFS and cardiac issues, will address the NOVA group on a special day and time. In addition to a broad overview of Chronic Fatigue Syndrome including case definition, clinical

findings, and key medical literature, Dr. Cheney will present on oxygen toxicity in CFS as well as his latest four part treatment protocol.

Dr. Cheney's "Oxygen Toxicity as a Controlling Factor for CFS" and "Cell Associated Therapy for Chronic Fatigue Syndrome: Is this the Next Frontier?" will be discussed.

This event is co-sponsored by the CFS & FM Support Group of Dallas/ Fort Worth, TX. See their page about Dr. Cheney at www.dfwcfdids.org/medical/cheney.html

CFS: Is Oxygen the Problem and Why?
A Four-Part Treatment

**Fairfax Gov't Center
The Board Auditorium
12000 Gov't Center Pkwy
Fairfax VA 22035**

6 - 9 pm, Free

Saturday April 25, 2009

**Registration requested
(703) 968-9818
[cfsupport-owner@
yahoogroups.com](mailto:cfsupport-owner@yahoo.com)**

Please refrain from wearing scented products. Bring your comforts.



SEMINARS IN LOUDOUN



Leesburg Group Location

Inova Loudoun Hospital
44045 Riverside Parkway
Conference Room A/B
Leesburg, VA 20176
Email us for Loudoun reminders.

April 4 - Rheumatologist

Brian Wallit, MD, MPH
Georgetown University, Wash, DC.
Looking at FM from a historical perspective; Fibromyalgia consciousness; recent understandings in brain science. Treatment issues.

June 6 - Holistic MD

Martha Calihan, MD, Leesburg, VA.
Combining many medicine traditions for each patient. Personalized care for optimal health and well being. Mind-Body Medicine, Functional Medicine, and Integrated care.

Sept 5 - TCM Practitioner

Jonathan Gilbert, NCCAOM, of N. Bethesda, MD. A nervous system can get stuck in a wide variety of imbalances, resulting in a wide variety of unusual symptoms. Chinese medicine offers the depth to calm frayed nerves and rejuvenate health.

Nov 7 - Holistic Health Counselor

Beth Eckhaus, of Leesburg, VA. A nutritionist and counselor, Beth's focus is on increasing a sense of well-being and integrating the mind, body and spirit and innovative ways to understand lifestyle and food.

NOVA ONLINE SUPPORT

We have two email lists and a big public website of resources:

Website

www.Geocities.com/CFSNova
Practitioners list, Q&A Our Way, news, books, articles on the web!

CFSupport List

Meeting notices, articles, notes on coping, encouragement and essays. Click on Subscribe at home page.

EGGdish List

Mind-body discussion of illness; gratitude attitude development as a treatment. Click on Gratitude Group on left side on home page.

HAVE YOU HEARD....

Last Year's Awareness Day Teleconference?

Listen online to support leader Elly and someone who recovered. www.WhenPushingStopsWorking.com/Audio.html. Hear them next in Doylestown, PA, in June.

About the new CFS Knowledge Center & ME/CFS Community?

There's a new resource center and community forum for people w/ CFS: cfsknowledgecenter.com

IMPORTANT NOTICE

We are Patient Peers!

Please be responsible: research and ask professionals about the suggestions you learn about. Our facilitators are patients, with no medical training. We honor and welcome the sharing of experience and information. Please only share things you feel comfortable saying publicly. There are no guarantees about confidentiality. Patient sharing, coping, enduring and advocating is our thing.

NOVA Calendar

**2 pm - Sully Govt'l Center
4900 Stonecroft Blvd
Chantilly, VA 20151**

Mar 21 - Peter Rowe, MD

Apr 18 - Discussion

(Apr 25 - Cheney, MD - Fairfax)

May 16 - discussion, Awareness

June 20 - discussion

**July 18 - Soc. Sec. Disability
Mitch Lambros, JD (10 AM)**

Aug 15 - TBD

Sep 19 - (10 AM)

Oct 17 TBD

Nov 21 TBD

Dec 19 - POTS Luck Social

Contact Us

Please let us know if your contact information changed or if you'd like to be removed from our lists. Please keep your email up to date at CFSupport.

EMAIL cfsupportowner@
yahoogroups.com

WEBSITES

www.geocities.com/cfsnova

groups.yahoo.com/group/
CFSsupport

PHONE

Elly Brosius (703) 968-9818
Toni Marshall (410) 647-7578

*Thank you to The CFIDS
Association for their assistance
with this mailing. www.cfids.org*