

Welcome Dr. Cheney!

CFS and Oxygen Toxicity

Special Event at the Fairfax County Governmental Center



What a *eventful* spring we are having! Spring is the time of awakening, the day of awareness, learning new things. Next we're having CFS pioneer and expert Paul R. Cheney, MD/ PhD, tell of his observations and current CFS treatments in a seminar made possible by the co-sponsorship of the CFS and FM Support

Group of Dallas and Fort Worth, TX. A seminar DVD is planned. See www.dfwcfd.org for availability.

As with any event, why we have them, is so some of us may find the next idea to *springboard* off of in hopes of feeling a little bit, or a bunch, better.

*Elly Brosius
& Toni Marshall*

Awareness Day

The blue ribbon of our logo is an Awareness Day symbol for CFS from way back, but life with a syndrome is anything but ribbons and bows.

Helping each other find creative ways to cope lest we be even more bored and frustrated to more tears and feats, we've been offering email and a significant web presence for 10 years, with more years of in person meetings and speakers.

To keep things evolving, we've changed the locations, added new speakers, added a monthly mind-body teleconference, an orthostatic intolerance phone group, and an email list for group gratitude journaling.

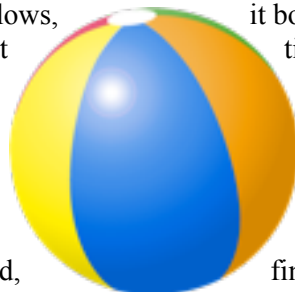
Join us in CF Support

by emailing cfsupport-subscribe@yahoo.com and registering. Call



LIFE AS A BEACH BALL - HOW DO YOU ROLL / ROLE PLAY?

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.

BY ELLY BROSIUS

OUR TELECONFERENCING: INFO, SUPPORT FOR, COPING WITH PAIN, FATIGUE, + + + +



The Calls of the Nervous System

Starting September '08, the Mitral Valve Prolapse Syndrome (MVPS/D) and OI meetings became teleconferences, more generally about all the nervous system symptoms. We include CFS and FM since dysAutonomia symptoms often coincide with those and POTS, NMH, IC, & IBS symptoms.

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.

**The Calls of the Nervous System
2nd Tuesday of every month
12-2 pm Eastern**

The EGG Calls for Gratitude

In late 2005, our new mind-body-attitude sister group of gratitude (EGG) began experimenting with teleconferencing as another way of connecting, supporting each other and ourselves, breaking up the isolation. In 2008, a yahoo group was added, EGGdish. Think of these as the NOVA ova.

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 look to make our expectations more reasonable and notice the stress in our "shoulds." We practice appreciation for saving energy, for creativity about old situations, and to accelerate any possible healing.

EGG Calls are monthly and only set about a month in advance.

**Elly's Gratitude Group Calls
April 29, 1 pm, Eastern
June 1st at 2 pm, Eastern**



**2009 Teleconference
Dial-In Number (218) 339-2699
with access code 5 6 8 3 9 4 #**



GROUPS: LOUDOUN FM & CFS SEMINAR GROUP - LEESBURG, VA

2009 Facilitator

Elly Brosius (703) 968-9818
 CFSupport-owner@yahoogroups.com
 Email for meeting reminders.

Location

Inova Loudoun Hospital
 44045 Riverside Parkway
 Conference Room A/B
 Leesburg, VA 20176
 Around the back of hospital,
 across from the Birthing Inn.

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.
www.IntegrativeFamily.com

September 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,
 especially from the hands of someone who has
 recovered from fibromyalgia, offers the depth
 to calm frayed nerves and rejuvenate health.
 Get a preview online:
WhenPushingStopsWorking.com (Audio)
www.TheGilbertClinic.com

November 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.
www.IntegrativeFamily.com

GROUPS: MORE DC / BALTIMORE AREA CFS & FIBROMYALGIA GROUPS

NOVA CFS & FM & OI Group

CFSupport-owner@yahoogroups.com
 Chantilly, 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
 Row beattyrk@wans.net

Baltimore CFIDS Network

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

Woodbridge Fibromyalgia

groups.yahoo.com/group/woodbridgefibromyalgia

Compass Support Timonium, MD

Therese compasssupport@comcast.net



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!

(410) 647-7578

**CDC CFS Call In Meeting
April 27**

The U.S. Centers for Disease Control and Prevention (CDC) will host a public meeting to gather input on its chronic fatigue syndrome (CFS) research program as it develops a 5-year plan on the following 5 categories of research topics: Studies of Defined Populations, Provider-based Patient Registries, In-hospital Clinical Studies, Laboratory Studies, & Provider and Public Educational Intervention Research. The meeting notice link: cdc.gov/cfs/meetings/2009_04.htm. A call-in option has been added to the public meeting on Monday, April 27. "Participants will be able to hear the full proceedings and time will be devoted to receiving comments from telephone callers." To register to attend by phone, send an email w/ your name, affiliation (if any), address, phone, fax and email address to cfsResearchPlan@cdc.gov

Subscribe to free CFIDS Association e-newsletter called *CFIDSLink* to follow this meeting and other CFS news.

For more regional and national events....

See our Events page at geocities.com/cfsnova/events.html

Also find our Clinical Trials, Media, Books, Resources and Newsletter pages.

Georgetown CFS Study

Aims to detect specific proteins in cerebrospinal fluid and to observe and document the spinal pressures at the time of lumbar puncture (spinal tap).

There are 2 visits: one for the screening which might take 3-4 hrs. The second visit is for the lumbar puncture (spinal tap) and after, the participant would be requested to stay at our clinic overnight and then would have his/her discharge by next day noon.

Study includes blood tests for sed rate, c-reactive protein, TSH, rheumatoid factor, anti-nuclear antibody, pregnancy, HIV, complete metabolic panel, complete blood count and differentials x 2, serum osmolality, lipid panel, basic metabolic panel, serum IgG, and amino acids; cerebrospinal lab tests: glucose, total protein, cell count, IgG, albumin, amino acids; clinical tests of isometric hand grip test (for the blood pressure, heart rate responses in relation with contraction exercise), pulmonary function testing, lumbar puncture, capsaicin skin test, allergy skin testing. Also an Acti-watch worn on non-dominant hand, 24 hrs for 1 week. A pre-paid envelope is given to return it. The watch scores the level of fatigue and estimates quality of sleep. Lab results are sent to the residential address in 2 weeks. A \$400 check is written to participants who complete the trial, w/ CFS and controls.

CFSAC Meeting

**May 27 and 28, 9 am - 5 pm
Wash, DC and call-ins**

A CFS Advisory Committee will be held at Dept. of Health & Human Services, Hubert H. Humphrey Bldf, 200 Independence Ave SW, Rm 800, Wash, DC 20201. 9 am to 5 pm. Agenda includes health agency updates and public testimony. Photo ID required. Pre-registration for public testimony with Dr. Wanda K. Jones, Deputy Ass't Secretary for Health (Women's Health), (202) 690-7650. Read testimony of your experience with CFS in person or by phone or have it read by someone else.

National Organizations

CFIDS Association of America (704) 365-2343
cfids.org

International Association for CFS/ME iacfsme.org

CFS/ME Knowledge Centr
cfsknowledgecenter.com

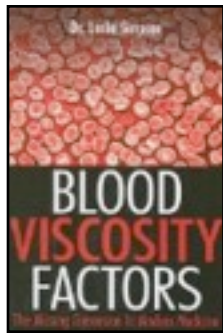
Fibromyalgia Network
(800) 853-2929
fmnetnews.com

National FM Association
(714) 921-0150
fmaware.org

National FM Partnership
(866) 725-4404
fmpartnership.org

FM Coalition International
(913) 384-4673
fibrocoalition.org

New Book by prior speaker Les Simpson



Blood Viscosity Factors, The Missing Dimension in Modern Medicine, by Leslie O. Simpson

Les spoke to our group in 1999 and 2001 about red blood cell shapes and supplements for improving circulation through the capillaries. Les' 2008 book brings together a series of essays on the impact of various

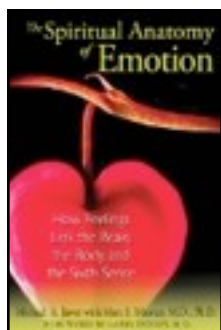
abnormalities on blood viscosity factors. It contains several hundred references to already published work in the field. Beginning with the finding that red blood cells proliferate in shape and are not just one toroidally shaped horde, the work offers unique insights into the role of aging and disease. One chapter is on Myalgic Encephalomyelitis, considered by some to be a subgroup of CFS. The book is of interest to those who prefer a more holistic view of science and the world, than is currently offered by the standard texts.

Leslie Simpson graduated from the Univ. of Otago in New Zealand in Zoology and later was awarded a Ph.D. in Experimental Pathology. He served for seven years in the World Health Organization.

Read about Les' work with CFS and Red Blood Cells:

www.geocities.com/redbloodcellresearch

New Book by prior speaker Mike Jawer



Spiritual Anatomy of Emotion: How Feelings Link the Brain, the Body, and the Sixth Sense

by Michael Jawer, forward by Larry Dossey, MD, is a cutting-edge examination of feelings, not thoughts, as the gateway to understanding consciousness. It offers a new perspective on immunity and stress, explains

how emotion is key to understanding out-of-body experience, apparitions, and other anomalous perceptions.

The less consciousness we have of our emotional being, the more physical disturbances we are likely to have -- ailments such as migraines, FM, chronic fatigue, and post-traumatic stress. The way we process our feelings provides a key to who is most likely to experience these phenomena and why. Emotion is a portal into extraordinary perception. This book is available in July 2009.

Mike Jawer spoke to our group in August 2005. Many of our members participated in his survey about unusual experiences. In our small group at that meeting, we had two people who had been hit by lightning, one who has been hit twice!

Read about Mike's work with people with CFS and other :

www.emotiongateway.com

OUR COMPUTER SUPPORT FOR NOVA & BEYOND...

CFSnova Website

Practitioners list, Q&A Our Way, disability and treatment resources, links, other groups, news, books, articles, more.
www.geocities.com/cfsnova

CFSupport Yahoo Group

From leaders only. Emails or “web-only” event reminders, articles and essays, news, notes on coping, encouragement and more.
groups.yahoo.com/group/CFSupport

mvps-d_oi_nova Yahoo Group

Almost “CFSupport Lite” with fewer notices with more emphasis on dysautonomia. Articles, encouragement, event reminders.
groups.yahoo.com/group/mvps-d_oi_nova

EGGdish Yahoo Group

Mind-body discussion of illness; gratitude attitude development. A place to post each our daily or occasional gratitude items.
groups.yahoo.com/group/EGGdish

HAVE YOU HEARD..,

Last Year’s Awareness Day Teleconference?

Listen online about Awareness Day and more awareness about syndromes and possibilities for healing. By Elly Brosius and Jonathan Gilbert. Hear them tell of their personal journeys, or their experiences helping others find feelings of recovery. On the web at WhenPushingStopsWorking.com/Audio.html or listen by phone by calling (641) 715-3413 and using code 312812. The next When Pushing Stops Working tour dates: June 16 in Doylestown, PA, and September 5 in Leesburg, VA.

We are Patient Peers!

Please participate responsibly. Research on your own and / or ask your trusted professionals about the suggestions you learn about at our group events. Our facilitators are not professionals, but people with syndromes. We 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 Sully Calendar

2 pm - 4 pm
Sully Govt’al Center
4900 Stonecroft Blvd
Chantilly, VA 20151

May 16 - talk, Awareness

June 20 - talk

July 18 - Applying for Social Security Disability Benefits, especially if you have CFS Mitch Lambros, JD (10 am)

Aug 15 -

Sep 19 - (10 am to noon)

Oct 17 -

Nov 21 -

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

MAIN WEBSITES

www.geocities.com/cfsnova

[groups.yahoo.com/group/
CFSupport](http://groups.yahoo.com/group/CFSupport)

PHONE

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Toni Marshall (410) 647-7578