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.dfwcfids.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

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.

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 CFSupport by emailing cfsupport-subscribe@yahoogroups.com and registering.

Call
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 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 NOV A 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
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: WhenPushing Stops Working.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

Daytime FM / CFS Support Group
Walk & Chat Group Sterling, VA
Patti layfam@hotmail.com
Adriana aekupe@aim.com
Row beatyrrk@wans.net

Woodbridge Fibromyalgia
groups.yahoo.com/group/woodbridgefibromyalgia

Bethesda FM/CFS Support Group
Andrea aflagiello315@yahoo.com
Marielle (301) 718-9326

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

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

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

**NOVA Sully Calendar**

2 pm - 4 pm
Sully Gov’t’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

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 WhenPushing Stops Working.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.

**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

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