

Bergen CFS-FM Support Group Newsletter

Meeting Report

The meeting was held at the New Milford Public Library where we felt very welcome. The April meeting is also scheduled to be held there. Directions are included in this newsletter.

Our speaker was energy healer Shoe-Zen Shin (Osamu Kamiyama). Master Shin spoke about qi energy and how he uses it to relieve clients of some of their symptoms. He demonstrated the technique on three members who said they felt some relief of symptoms. He compared it to acupuncture without the needles. The Bergen CFS-FM support group, its co-leaders, and our parent organization the NJCFA do not necessarily endorse any particular therapies, but offer this as an opportunity to learn about some of the alternative and/or complimentary therapies.

Events – Our parent organization, the NJCFSA, is holding a Gala in May to raise funds, and to honor three people who have been very significant in the organization. The flyer appears at the end of this newsletter. We hope some of you might be able to attend. You may want to pass the information to your doctors or people who might be interested.

CFS in the News www.cfids.org

CFS IS A NEWSMAKER

Tune in to **CNN Headline News, Comcast Cablevision channel 58**, from **Wednesday, March 26, through Wednesday, April 2**, for a segment of **Comcast Newsmakers** featuring Dr. Benjamin Natelson, professor of neurosciences at the University of Medicine and Dentistry of New Jersey. This will be the first of a two-part series focusing on CFS and will provide a general overview of the illness.

In the second part, titled "Pre-sickness and the Wellness Track," Dr. Natelson will discuss those people who experience fatigue and pain but don't meet all the diagnostic criteria for CFS or FM. He works with such "pre-patients" to develop a wellness program to enable them to cope with their illness in order to prevent it from progressing to CFS or FM. This segment will air from **Wednesday, April 16, through Wednesday, April 23**.

Both segments will air at various times throughout the day.

Social

Social Director, Frank Kawa, has set a date for a gathering

Wednesday April 2nd

Luncheon

at

The Seville Diner

289 Broadway

Westwood

The group will be there from 1:30 PM until about 3 PM.

Just show up.

If you have any questions or wish to let Frank know you are coming, you can call him at 201-768-4111. You do not need to contact Frank to attend.

Directions to New Milford Library [location of April meeting]

Meeting of the Bergen CFS/FM Group is in small conference room in back of Library reserved by Judy Machacek and NJCFSA

From Route 4, traveling East:

- Follow Route 4 past Hackensack Ave, (past Diner and Hooters)
- Exit right at River Road, toward New Milford/Teaneck
- Bear left at "T" in road (will see FDU beyond)
- At light, turn Left onto River Rd
- Follow River Road, to the 4th light, (about 2 miles) To Ridge St. (Left side of road says River Lane, !?)
- Turn Right at Ridge St., go one block to bend in road= Dahlia Rd.
- Turn Right onto Dahlia Rd. Library is on Right, parking lot in rear

From Route 4, traveling Westbound:

- Exit at River Road, New Milford (just past Belle Ave Exit)
- Bear Right at bottom of hill, go to light = River Rd.
- Follow River Road, to the 4th light, (about 2 miles) To Ridge St. (Left side of road says River Lane, !?)
- Turn Right at Ridge St., go one block to bend in road= Dahlia Rd.
- Turn Right onto Dahlia Rd. Library is on Right, parking lot in rear

From towns North of New Milford:

A: Take Kinderkamack Rd south.

- Turn left at River Edge Rd (down the hill)
- Continue over tracks and up to River Rd to light "T" in road)
- Turn right onto River Rd and follow south, past Shop Rite
- Total lights from River Edge Ave to Ridge Street is 4 lights
- Now turn Left onto Ridge Street, (sign says River Lane on right,!?)
- go one block to bend in road=Dahlia
- Turn Right onto Dahlia RD, Library is on Right, parking lot in rear.

B: Take Boulevard south from Oradell.

- Follow Boulevard south until you see Blue Sign for Library at Ridge St.
- Turn Right onto Ridge Street, follow curving road, bearing left until "T" in RD.
- Turn Left onto Dahlia Rd. Library is on Right, parking lot in rear.

It is strongly recommended that you do not follow MapQuest - too many back streets and confusing turns.

Surgery, Anesthesia and CFS/FM/MCS

Excerpts from *Melissa Kaplan's Chronic Neuroimmune Diseases Information on CFS, FM, MCS, Lyme Disease, Thyroid, and more...* Last updated April 19, 2007

Full article can be found at <http://www.anapsid.org/cnd/drugs/anesthesia.html>

Compiled by Melissa Kaplan

Anesthesia

Persons with CFS/FM/MCS often do not respond to drugs, including anesthetics, the way healthy people do, or the way that people with other diseases and disorders do. This makes going in for surgery, whether inpatient or outpatient, doubly risky for PWCs.

RECOMMENDATIONS BY CHARLES W. LAPP MD

Hunter-Hopkins Center

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Recommendations For Persons With CFS Or Fibromyalgia Who Are Anticipating Surgery

CFS is a disorder characterized by severe debilitating fatigue, recurrent flu-like symptoms, and neurocognitive symptoms such as difficulties with memory, concentration, comprehension, recall, calculation and expression. A sleep disorder is not uncommon. All of these symptoms are aggravated by even minimal physical exertion or emotional stress, and relapses may occur spontaneously. Although mild immunological abnormalities (T-cell activation, low natural killer cell function, dysglobulinemias, and autoantibodies) are common in CFS, subjects are not immunocompromised and are no more susceptible to opportunistic infections than the general population. The disorder is not thought to be infectious.

Persons with CFS frequently re-activate latent herpes group viruses, which may produce a mild, subclinical hepatitis with slight elevations of the transaminases. Thus, hepatotoxic anesthetic agents should be avoided because they could potentiate the liver problem or even provoke fulminant hepatitis.

Intracellular magnesium and potassium depletion has been reported in CFS. For this reason, serum magnesium and potassium levels should be checked pre-operatively and these minerals replenished if borderline or low. Intracellular magnesium or potassium depletion could potentially lead to cardiac arrhythmias under anesthesia.

Up to 97% of persons with CFS demonstrate vasovagal syncope (neurally mediated hypotension) on tilt table testing, and a majority of these can be shown to have low plasma volumes, low RBC mass, and venous pooling. Syncope may be precipitated by catecholamines (epinephrine), sympathomimetics (isoproterenol), and vasodilators (nitric oxide, nitroglycerin, α -blockers, and hypotensive agents). Care should be taken to hydrate patients prior to surgery and to avoid drugs that stimulate neurogenic syncope or lower blood pressure.

Allergic reactions are seen more commonly in persons with CFS than the general population. For this reason, histamine-releasing anesthetic agents (such as pentothal) and muscle relaxants (curare, Tracrium, and Mevacurium) are best avoided if possible. Propofol, midazolam, and fentanyl are generally well-tolerated. Most CFS patients are also extremely sensitive to sedative medications -- including benzodiazepines, antihistamines, and psychotropics -- which should be used sparingly and in small doses until the patient's response can be assessed.

Finally, HPGA Axis Suppression is almost universally present in persons with CFS, but rarely suppresses cortisol production enough to be problematic. Seriously ill patients might be screened, however, with a 24 hour urine free cortisol level (spot or random specimens are usually normal) or Cortrosyn stimulation test, and provided cortisol supplementation if warranted.

Summary Recommendations:

- Avoid hepatotoxic anesthetic agents
- Insure that serum magnesium and potassium levels are adequate
- Hydrate the patient prior to surgery
- Use catecholamines, sympathomimetics, vasodilators, and hypotensive agents with caution
- Avoid histamine-releasing anesthetic and muscle-relaxing agents if possible
- Use sedating drugs sparingly
- Consider cortisol supplementation in patients who are chronically on steroid medications or who are seriously ill.

Relapses are not uncommon following major operative procedures, and healing is said to be slow but there is no data to support this contention.

RECOMMENDATIONS BY PAUL CHENEY MD AND PATRICK CLASS MD

The following two quotes appear frequently throughout the CFS/FM/MCS support group and website literature:

"I would recommend that potentially hepatotoxic anesthetic gases not be used including Halothane. Patients with Chronic Fatigue Syndrome are known to have reactivated herpes group viruses which can produce mild and usually subclinical hepatitis. Hepatotoxic anesthetic gases may then provoke fulminate hepatitis. Finally, patients with this syndrome are known to have intracellular magnesium and potassium depletion by electron beam x-ray spectroscopy techniques. For this reason I would recommend the patient be given Micro-K using 10mEq tablets, 1 table BID and magnesium sulfate 50% solution, 2cc IM 24 hours to surgery. The intracellular magnesium and potassium depletion can result in untoward cardiac arrhythmias during anesthesia. **For local anesthetics, I would recommend using Lidocaine sparingly and without epinephrine.**"

Paul R. Cheney, MD, PhD, 1992
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"Suggestions on anesthesia include using Diprivan (propofol) as the induction agent along with nitrous oxide and isoflurane (Forane) as the maintenance agent. The ones to avoid are histamine releasers that include sodium pentothol as well as a broad group of muscle relaxants in the Curare family, including Tracrium and Mevacurium."

Patrick. L. Class, MD, 1996
Anesthesiology
300 S. Arlington Avenue
Reno 89501
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RECOMMENDATIONS BY MICHAEL J. ROSNER MD

Probably best known amongst PWCs/FMs for his identification of craniovertebral stenosis (creating a malformed or abnormally small opening of the spinal canal, known as the [Chiari formation](#)), discusses the importance of the patient's posture during the surgical procedure: "For those patients with canal stenosis or hypoplastic posterior fossa, the most important component of anesthesia is a neutral neck position and avoidance of hypotension. The former may increase cord compression and the latter may decrease blood flow to the spinal cord. Together, the effect may be severe. This may also be part of the mechanism by which both surgery and trauma are linked in some individuals to the development of their FMS/CFS. I doubt that the specifics of different anesthetic regimes will matter too much beyond the above."

Michael J. Rosner, MD
Park Ridge Hospital Naples Rd Fletcher, NC 28732 828-684-8501

RECOMMENDATIONS BY GRACE ZIEM PhD AND JAMES McTAMNEY PhD

From the abstract of "Profile of Patients with Chemical Injury and Sensitivity"

"...Agents whose exposures are associated with symptoms and suspected of causing onset of chemical sensitivity with chronic illness include gasoline, kerosene, natural gas, pesticides (especially chlordane and chlorpyrifos), solvents, new carpet and other renovation materials, adhesives/glues, fiberglass, carbonless copy paper, fabric softener, formaldehyde and glutaraldehyde, carpet shampoos (lauryl sulfate) and other cleaning agents, isocyanates, combustion products (poorly vented gas heaters, overheated batteries), and medications (dinitrochlorobenzene for warts, intranasally packed neosynephrine, prolonged antibiotics, and

general anesthesia with petrochemicals). Multiple mechanisms of chemical injury that magnify response to exposures in chemically sensitive patients can include neurogenic inflammation (respiratory, gastrointestinal, genitourinary), kindling and time-dependent sensitization (neurologic), impaired porphyrin metabolism (multiple organs), and immune activation. " Abstract published in Environmental Health Perspectives, 1997, volume 105 (Suppl 2), pages 417-436. Based on a paper presented at the Conference on Experimental Approaches to Chemical Sensitivity held 20-22 September 1995 in Princeton, New Jersey.

Dr. G. Ziem

1722 Linden Avenue Baltimore MD 21217 410-462-4085 Fax: 410-462-1039

Recommendations by Robert Bennett MD Oregon Fibromyalgia Foundation
[Guidance for Fibromyalgia Patients who are having Elective Surgery](#)

RECOMMENDATION BY ??

(This unattributed quote is found online at various CFIDS sites.)

Anesthesia Protocol: Patient Cannot Receive Any Histamine-Releasing Drugs

"I have used the following anaesthesia protocol with success during surgery on CFS patients. First, I perform skin tests for all the agents I am considering using with the patient. With CFS patients, I recommend Diprivan (propofol) as the induction agent; Versed (midazolam), fentanyl (a short-acting narcotic) and droperidol (an anti-nausea agent) during the anaesthetic; and a combination of nitrous oxide, oxygen and iso-flurane (commonly called Forane) as the maintenance agent."

"In contrast to the above agents, there is a group of commonly used anaesthetic agents which are known histamine-releasers and are probably best to be avoided by CFS patients. This group includes the thiobarbiturates such as sodium pentothal, which is probably the most common induction agent, but is a known histamine-releaser. In addition, there are a broad group of muscle relaxants in the Curare family, name Curare, Tracrium and Mevacurium, which are also potent histamine releasers and should be avoided by CFS patients. Since so many of these histamine-releasing agents are commonly used during emergency surgery, it would be advisable for you to wear a medical alert bracelet in the event you are unconscious and would have to have an anaesthetic. I would mention on the bracelet that you cannot receive any histamine-releasing drugs."

From [Gasnet.org](#): Anaesthetic Considerations in the Patient with Rheumatoid Arthritis

"Rheumatoid arthritis (RA) is a multisystem autoimmune disease with many anesthetic implications. Patients with RA may challenge the anesthesiologist at the time of tracheal intubation because cervical spine instability. In addition, temporomandibular joint (TMJ) or arytenoid joint immobility may limit safe access to the airway. The preoperative anesthetic assessment must focus on possible airway difficulties. Patients must be questioned and examined to elicit evidence of neck pain, limitation of cervical spine movement, nerve root impingement or spinal cord compression. Lateral C-spine flexion-extension X-rays are indicated in patients with cervical spine symptomatology to assess the possibility of cervical spine subluxation. The need for these X-rays in completely asymptomatic patients remains controversial; however, one should keep in mind case reports of neurological damage following direct laryngoscopy and intubation in asymptomatic patients. Patients with cervical spine instability should generally be intubated and positioned awake before surgery to avoid neurological injury. The TMJs must be examined to ensure that mouth opening and anterior subluxation of the mandible will permit direct laryngoscopy. Patients demonstrating stridor or hoarseness require awake direct or indirect laryngoscopy to assess the possibility of arytenoid involvement and determine the size of the glottic opening. Finally, the larynx may be displaced from its usual location by erosion and generalized collapse of the cervical vertebrae."

D. John Doyle, PhD, MD

[Medical Conditions with Airway Considerations](#)

Post-Polio Health International

[Summary of Anesthesia Issues for Post-Polio Patients](#)

Topical Anesthetics

For those allergic to lidocaine (or any of the 'caines), beware of this neat little gadget:

Lidocaine Iontophoresis Reduces Pain Of Needle Sticks For Kids

A study published in The Journal of Pediatrics shows that lidocaine iontophoresis reduces the pain children feel from needle sticks. Iontophoresis is a needle-free method of delivering certain types of medication directly into and through the skin using a mild, low-level electric current.

Study results concluded patients receiving lidocaine iontophoresis were noted to have a three-fold reduction in pain compared with placebo prior to IV catheter placement.

The pediatric application of iontophoresis, marketed as Numby Stuff(R), is a needle-free method of delivering lidocaine(R), lomed's brand of anesthetic medication, directly into the skin using a mild, low-level electric current from a small, battery-powered dose controller. In as little as 10 minutes, the skin and underlying tissue becomes completely numb up to a depth of 10 millimetres, allowing the physician or nurse to proceed with local dermal procedures. Numby Stuff is currently being used in hospitals nation-wide for the delivery of anesthesia prior to IV starts, drawing blood, performing a minor surgical procedure such as a skin biopsy, port access, performing a lumbar puncture and any other procedure over intact skin where the skin needs to be numbed.

Excerpted from [Doctor's Guide](#).

Surgery

Surgeons, anesthesiologists and support staff need to be aware of the following anomalies typically found in persons with CFS/FM/MCS:

- neurally mediated hypotension (NMH) or [orthostatic hypotension](#) (OI)
- low red blood cell count
- low blood plasma volume
- [hypercoagulation](#) (thick blood - a low sed rate [0-5] is often seen)
- alkalotic (urine pH < 6, venous blood pH > 7.4)
- drug and food sensitivities
- [chemical sensitivities](#), including plastics, vinyl, disinfectants
- poor absorption of nutrients in the gut
- leakage out of the gut ("[leaky gut](#)") of non-assimilable particles
- abnormally low (up to 50% below normal) oxygen release from red blood cells
- 80+% chance of severe herxheimer effect from some antibiotics
- many supplements act as blood thinners and anticoagulants
- low NK levels, or abnormal numbers of immature NK cells, coupled with hyperactive Th2 immune activity

[Hospitalization For The Chemically Sensitive](#)

Selene Anema, RN. Tips for hospital staff covering patient and surgical suite environment, drugs, anesthesia, and more.

Next Meeting

The next meeting will be Sunday April 20th from 2-4 PM at the New Milford Public Library [directions included in this newsletter]. This will be an open discussion meeting.

This newsletter is intended for CFS patients in the area of this support group. The purpose is to share information and support. If you have questions about meetings please contact: Pat LaRosa at pat.njcfsa@larosas.net, Nancy Visocki at ngv.njcfsa@verizon.net, Judy Machacek at judymachacek@msn.com or Frank Kawa at 201-768-4111.