

The Carousel Network
Chronic Neuroimmune Diseases
Information & support for Sonoma County

Chronic Fatigue Syndrome (CFS/CFIDS)

Fibromyalgia (FM)

Multiple Chemical Sensitivities (MCS)

P.O. Box 366 - Fulton, CA 95439-0366

Volume IX No. 3

May/June 2003

Meeting Dates: May 10 & June 14

Environmental Services Prevention & Planning Conference Room B
3273 Airway Drive, Santa Rosa

Topic: May 10: Wayne Anderson, PA - Lyme Disease/Treatment

June 14: Ange Stephens, MFT - Psychotherapy for People with

Chronic Illnesses

General Meeting Format

Timing will be adjusted as necessary to meet video and speaker

needs.

2:00-3:30 PM Program (topical discussion, speaker, or video)

3:30-4:00 PM Q&A, small group discussion may go on after

Meeting Dates for 2003:

May 10 Jun 14 Jul 12 Aug 9 Sep 13 Oct 11 Nov 8 Dec 13

Meetings are on the second Saturday of each month. The Carousel Network

Chronic Neuroimmune Diseases
Information & Support Group for Sonoma County
P.O. Box 366 Fulton, CA 95439-0366

Your expiration date appears on
your label... please renew early!

The Carousel Network
CFS/ME/FM Support Group
P.O. Box 366
Fulton, CA 95439-0366

Board Members

Melissa Kaplan, President

Suzi Valeri, Vice President

Dolores Rhoads, Treasurer

Carol Hansen, Member-at-Large

Loretta Beach, Member-at-Large

Page 2

Meeting Second Saturday, 2 p.m.

DHS Environmental Services Prevention & Planning

Large Conference Room, Suite B
3273 Airway Drive, Santa Rosa
For info: Melissa Kaplan (707) 575-4170,

during daytime hours, please.

PLEASE: NO FRAGRANCES AT MEETINGS AS
SOME MEMBERS ARE CHEMICALLY SENSITIVE.

SUBSCRIPTION RATE: \$20 a year (6 bimonthly issues). Make checks payable to THE CAROUSEL NETWORK, P.O. Box 366, FULTON, CA 95439-0366. In hardship cases, please contact MELISSA KAPLAN, (707) 575-4170, for a hardship waiver application.

DONATIONS may be made payable to The Carousel Network and mailed to our address. If you would like to donate media related to CND, or equipment, etc., please contact us.

DISCLAIMER: Our support group is an all-volunteer, nonprofit organization. We do not give medical advice or endorse products or treatments. Members of our group treat with various mainstream and alternative therapies, sometimes in combination. If you have CFS/FM/MCS, we encourage you to work with an informed health care professional as you make choices and decisions about your own treatment.

CFS/FM/MCS LIBRARY: Contact Jerry Sundahl (707) 546-1460, regarding checking out library materials.

ADVERTISING: Business card (2" x 3V2"). Rate: \$6 per month, or \$15 for four months, paid in advance.
.Disclosure for Grantors and Contributors

The Carousel Network was granted and maintains tax-exempt status under Section 501 (a) of the Internal Revenue Code. More specifically, The Carousel Network is an organization described in Section 501(c)3,509(a)(1),and170(b)(1)(A)(vi).

As required by the above IRS sections, The Carousel Network makes its annual information return (IRS Form 990) available for public inspection for three years. Also available are The Carousel Network's exemption application, supporting documents, and exemption letter. These documents are on file with the Carousel Network's president and available at 4th Monday meetings.

Visit The Carousel Network Online!
www.cndsinfo.net

Contents

Letter from the Editor	2
Symptom List Update	3
Toxic Molds	6
West Nile	6
Fruit Juiceand Urinary Tract	

7	
Smelling Good	7

Hashimoto's Disease	8
---------------------	---

C. Pulmoni	9
Alternate Definitions	10
Neighborly Smoke?	10
SARS	11
Glucose Intolerance/Memory	

12	
Sleep	13
A Family Affair	13
Humor	7,10,12
Privacy	13

Letter From the Editor

So many of us have multiple afflictions that this issue is filled with some of the other things that may plague us. Just because we present with one disorder does not make us immune to others. So this issue has some articles for information only, as future issues will also.

We are not all doctors and make no claim to know everything. But among us we have a wealth of experience. On the other hand, we do identify with other sufferers, sometimes too much. All of this may not pertain to you and your unique situation. But our condition being as it is, it is no wonder that so many of us are on or applying for disability.

The lead article is a compilation of some of the latest thinking about CFIDS and FM and other disorders. We may be asked why these are so serious. The information, gleaned from a number of sources, may help. The symptoms do not all apply to everyone, nor is it necessary to have all of them to have the syndromes. Researchers and doctors in the field are beginning to get a lead to understanding these disfunctional immune or central nervous system disorders.

Our next two speakers will add other perspectives to the discussion. Do not be put off by the topics, please. Any of us living in Northern California might encounter the Lyme spirochete at any time. Now that our illnesses are considered real, psychiatrists may also have something to offer us (apart from meds?).

Carol Hansen

www.newsletter.cdsinfo.net

Permission to reprint is granted to nonprofits for educational purposes. Please reprint in full, sourcing the author, TCN, and any other original source if indicated. Submissions preferred via email or on disk in .txt format, but if it's readable, any form is fine.

Page 3

Master Symptom List

Melissa Kaplan

As research continues into chronic fatigue syndrome (CFS), fibromyalgia syndrome (FMS), chronic myofascial pain (CMP) and chronic Lyme disease, the differences between these disorders is blurring. Twenty years ago, the organism responsible for Lyme disease was discovered. Researchers, mostly underfunded private researchers in labs around the world, continue to subject various bodily substances harvested from people with CFS and FM to try to find any unique markers, genetic or microbial, that may cause these illnesses. Why some people who suffer physical trauma, as from auto accidents, go on to develop FMS or CMP, and why others don't, is another of life's mysteries still to be teased out.

What we do know is that it is the rare patient who meets the diagnostic criteria of only one of these diagnoses. Far more common are people who meet the definitions of two or more. We also know that those who do meet the criteria for these diagnoses may not experience every known symptom for each. (Okay, so it often feels like we have every symptom, all at the same time, but fortunately for most of us, the numbers and severity/intensity wax and wane as the years go on.)

There are many different symptom lists for the different disorders. They are usually found in disease-specific website or books, but rarely do they appear all together, co-mingled. Several years ago, I compiled a combined CFS/FMS symptom list, publishing it in this newsletter and making it available online at my website. This new Master Symptom List takes the old list one—or two—steps forward by including symptoms for CMP and Lyme. It should be noted that, with the exception of birth defects attributed to it, the symptoms for Gulf War Illness (GWI) are the same as those for CFS. It may ultimately be found that differences in GWI may be attributed to what actually triggered the illness in the individuals so affected: exposure to chemicals (including leaded fuel exhaust and oil fires), vaccines, and other substances they were required to ingest or have injected.

A Note on Lyme Disease: It is estimated that 30-50 percent of acute Lyme disease patients develop chronic Lyme. That is, despite antibiotic and other treatment, the *Borrelia burgdorferi* organism remains alive and well, periodically causing a worsening of symptoms or causing new symptoms to appear. Two-thirds of those bitten by an adult tick or tiny tick nymph never even know they've been bitten, and not everyone who is bitten develops the bull's-eye rash that the CDC stipulates as one of its diagnostic criteria; many people with Lyme never exhibit any type of rash. There are over 300 known strains of Bb and at least six genotypes, increasing the difficulty in testing people for its presence and making the clinical diagnostic criteria too rigid. Many of those who go on to develop chronic Lyme do so because of not getting properly diagnosed right away, or not getting the appropriate treatment (too many doctors still prescribe too-short a period of antibiotics). Others keep testing negative for the disease because the tests used do not detect the strain they have, or the Bb is in one of its many presently undetectable morphs.

A Note on Symptoms: many of these are symptoms common to other diseases. Getting a proper diagnosis for CFS, FM, CMP, Lyme and other tick-borne diseases is as much ruling out other diseases as it is looking at the clues in dozens of tests and the actual physical exam. There are far more symptoms than are listed below. The full list of symptoms for each

category can be found in the Diagnosis section of my Chronic Neuroimmune Diseases website, www.anapsid.org/cnd.

AUTONOMIC NERVOUS SYSTEM/ENDOCRINE/IMMUNE/HORMONE

Abnormal sensitivity to hot or cold
Allergies (nasal, other; new, increased or worsening)
Canker sores (frequent)
Chills and/or shakes when hungry (may occur instead of feeling hungry)
Cold hands and feet
Feeling hot or cold often
Flu-like symptoms, on-going or recurrent after initial gradual or acute onset; includes mild fever (99.5-101.5 F / 37.5-38.6 C), chills, extreme fatigue after minimal exertion
Hair loss (alopecia)
Lymph nodes painful, swollen (in neck; under arms)

Page 4

CARDIOPULMONARY/RESPIRATORY/CIRCULATORY

Cardiac abnormalities (mitral valve prolapse; myocarditis; tachycardia; palpitations; dysrhythmia)
Cough
Dyspnea (out of breath) or shortness of breath (air hunger) after minimal or no exertion
Heart attack
Heart palpitations
Heart pounds so hard it shakes body, bed
Pulse skips
Serious rhythm disturbances of heart
Sighing, frequent, not related to mental/emotional state

CENTRAL NERVOUS SYSTEM/NEUROLOGICAL/NEUROPATHIC/OTOLOGIC

Abnormal CAT, MRI and/or SPECT scans
Alcohol intolerance (Aseptic meningitis
"Brainfog"; inability to think clearly
Difficulty moving tongue to speak
Diminished or absent reflexes
Fainting or blackouts; feeling like you might faint
Headaches (frequent, severe, recurring)
Hearing fluctuations (sounds fade then return)

COGNITIVE FUNCTION

Becoming lost in familiar locations when driving
Difficulty with simple calculations (e.g., balancing checkbook)
Difficulty expressing ideas in words
Difficulty moving your mouth to speak
Difficulty making decisions
Slowed and/or slurred speech
Stuttering; stammering
Transposition (reversal) of numbers, words and/or letters when you speak and/or speak
Word-finding difficulty
Using the wrong word

DIGESTIVE/HEPATIC

Bloating; intestinal gas
Decreased appetite
Digestive chemicals (acid, enzymes) reduced or absent
Esophageal reflux; heartburn
Frequent constipation
Frequent diarrhea
Food cravings (especially carbohydrates, sweets)
Food/Substance intolerance
IBS
Liver function impaired; mild abnormalities

EQUILIBRIUM/PERCEPTION

Bite your cheeks or tongue frequently
Bump into things frequently
Difficulty discriminating printed matter despite proper vision correction
Distances (difficulty judging when driving; when putting things down on surfaces)
Dizziness or vertigo
Dropping things frequently
Dysequilibrium (balance problems)
Impaired coordination
Loss of balance when standing with eyes closed
Perception (not quite seeing what you are looking at)

EYES/VISION

Acuity changes not related to prescription changes
Blind spots
Blurred vision
Conjunctivitis
Diminished visual acuity in absence of actual vision change
Drooping eyelid
Double vision
Eye pain
Flashes of light perceived peripherally
Optic neuritis or atrophy

HEAD/NECK/MOUTH

Bell's palsy (facial paralysis, one or both sides)
Bruxism (grinding/clenching teeth)
Canker sores
Dizziness when you turn your head or move
Dry chronic cough
Dry eyes, nose and mouth (sicca syndrome)
Pain in ears, palate, gums
Periodontal disease
Prickling pain along skin of jaw
Problems swallowing, chewing

MUSCULOSKELETAL

Arthritic pain that migrates from joint to joint
Carpal tunnel syndrome
Frozen shoulder
Intermittent joint swelling
Joint aches (arthralgia)
Joint pain, without redness or swelling
Loss of tone
"Lumpy, bumpy" long muscles
Morning stiffness
Muscle aches (myalgia)

Page 5

cont. from p.4

PAIN SYMPTOMS

Abdominal pain
Chest pain
Generalized pain
Shooting or stabbing pains
Painful tender points (FMS: 11 out of 18 tender points)

PSYCHOLOGICAL SYMPTOMS/MOOD/EMOTIONS

Abrupt/Unpredictable mood swings
Anxiety or fear for no obvious reason
Appetite increase/decrease
Decreased self-esteem
Depression or depressed mood
Feeling helpless and/or hopeless
Feeling worthless
Frequent crying for no reason
Helpless/Hopeless feelings
Inability to enjoy previously enjoyed activities

SENSITIVITIES

Acute or abnormal reactions to medications
Alteration in taste, smell, and/or hearing
Chemicals (alcohol, medications; lower tolerance for)
Food sensitivities
Increased perception of and sensitivity to noise
Light sensitivity
Sensitivity to odors (able to detect and/or react in concentrations far lower than before and that healthy people cannot smell)

SKIN/NAILS

Abnormal scarring

Blotchy or mottled skin
Bruise easily
Bruises may take longer to appear, and/or longer to fade
Bull's-eye (Erythema migrans) on light skin (resembles a bruise on dark skin)
Dermographia (minor scratch pressure on skin leaves vivid red welts)
Dry, itchy skin
Easily scar
Eczema or psoriasis
Fragile nails

SLEEP SYMPTOMS

Abnormal brain activity in stage 4 sleep
Altered sleep/wake patterns (alert/energetic late at night, sleepy during day)
Difficulty falling asleep
Difficulty staying asleep (frequent and/or prolonged awakenings)
Hypersomnia (excessive sleeping)
Myoclonus (restless leg syndrome; occasional jerking of entire body)
Nightmares (frequent, extremely vivid and/or disturbing)
Unrefreshing/Non-restorative sleep

UROGENITAL/REPRODUCTIVE

Decreased libido
Endometriosis
Frequent urination
Incontinence
Impotence
Infant: premature; low birth weight; low muscle tone; failure to thrive
Interstitial cystitis
Miscarriage or stillbirth
Pelvic and/or rectal pain
Worsening of PMS

OTHER

Abnormal or other changes in sweating
Activity level reduced to less than 50% of pre-onset level
Burning sensation (internal and/or external)
Changed voice
Changes in sweat odor/body odor
Delayed reaction to overactivity/exertion (onset 24-48 hours after exertion)
Fatigue, prolonged, disabling, made worse by exertion or stress
Hair loss (not related to age, hormones, diet, medication)
Hands hurt excessively when put in cold water
Handwriting changes, altering signature and/or other writing

COMMON CO-INFECTIONS AND DISORDERS

Babesiosis
Cytomegalovirus (CMV)
Epstein-Barr virus (EBV)
Ehrlichiosis
Herpesvirus
HHV6
Iron deficiency
Mercury or other metal toxicity
Mycoplasma
Systemic mold and/or mold sensitivities

Sources:

Fibromyalgia & Chronic Myofascial Pain. Devin Starlanyl & Mary Ellen Copeland. 2001. New Harbinger Publications Inc.
www.sover.net/~devstar
Chronic Fatigue Syndrome, Fibromyalgia and Other Invisible Illnesses. 2001. Katrina Berne. Hunter House Publishing.
www.livingwithillness.com
The Interface of Chronic Lyme Disease, CFS and FM. Bonnie Gorman. In, The Update. Massachusetts CFIDS & FM Association. 18(3):1, 35-40. Fall 2002. www.masscfids.org
Arthritis Foundation www.arthritis.org
American College of Rheumatology, www.rheumatology.org
Fibromyalgia Network, www.fmnetnews.com
Jay Goldstein, MD, www.drjgoldstein.com
Centers for Disease Control & Prevention: CFS: www.cdc.gov/ncidod/diseases/cfs/index.htm

Mold

Insurance companies have recently instituted a policy of excluding mold from their coverage, both in buildings and vehicles. It is costly and difficult to completely eradicate mold. If mold causes an illness it can become even more expensive.

Toxic molds have plagued mankind since grain storage began. There are several types. They usually occur in hot humid areas but can grow in temperate zones. Most often mold infection is by eating, but can occur through the skin or by breathing it in.

It is difficult for doctors to recognize mold except when many people are affected. Molds produce mycotoxins which are the agents that act as poisons on humans and animals. Each type of mold produces a different toxin. Occurring on wheat, Ergot or St. Anthony's fire produced LSD (lysergic acid diethylamide, causing mass murder and mayhem. Another ergot toxin is belladonna.

Many mycotoxins are no longer such a threat because of better storage and handling measures. Beriberi disappeared when moldy rice was no longer sold. Strict control of feed and grain remain necessary to protect our health.

Some molds are beneficial such as those used in the production of cheese and salami or in fermentation. Some are used as treatments for metabolic conditions like Parkinson's. Others can be toxic, immunosuppressive, mutagens or carcinogens especially to the liver.

There are several methods for removing mold. Try one of these in solution with water.

Bleach

Hydrogen Peroxide

Oregano Oil

Tea Tree Oil

White Vinegar

Perhaps the worst mold at present is the one that causes sick building syndrome. The mold that causes this is 40 times more toxic when inhaled.

West Nile

People with compromised immune systems and people over 60 are more vulnerable to the West Nile virus which is expected to be present in all 50 states this summer. The virus is spread by mosquitoes that feed on infected birds. 250 people died from it last year out of 4,000 infected. Most people bitten do not even have symptoms, while it is deadly for others. There is no treatment for this virus.

The worst symptoms is W.N. encephalitis. Symptoms: brain inflammation, high fever, severe headache, disorientation, convulsions and paralysis. Some treatments are promising.

It has been recommended that people remove any sources of standing water from your property. Use insect repellent outside or wear a hat long sleeves, and long pants. Protect hands, face neck and ankles. Put screens on all windows and doors.

West Nile virus may have an almost unique way of infecting and killing cells. Researchers at the University of Pennsylvania traced its viral pathway. The virus disrupted cell membranes (mitochondria). Deleting part of the virus slowed the inflammation process. But will this lead to a vaccine? Only one other virus has this mechanism for infection. The virus may be of the flavivirus type.

Fruit Juice Intake tied to Reduced Risk of UTI

Consumption of fresh juices and fermented milk products appears to protect women from urinary tract infections (UTIs), according to new research. Investigators based in Finland found that women who regularly drink fresh juices and eat yogurt and cheese may be less likely than others to develop UTIs. The authors found that women who drank at least one daily glass of fresh juice were 34% less likely than other women to develop an UTI. Women appeared especially protected from UTIs if they drank juices made from berries, the report notes.

Also women who reported eating milk products that contain probiotic bacteria —such as yogurt and cheese—at least three times each week were almost 80% less likely to have developed a UTI than women who ate these foods less frequently.

These findings are based on surveys of the eating habits of 139 women who had developed a UTI within 2 weeks prior to the survey, and 185 women who had not experienced UTIs within the past 5 years.

Women who had not experienced a recent UTI reported higher consumption of fresh fruit juices and milk products containing probiotic bacteria.

The authors speculate that certain foods and drinks may ward off UTIs by modifying the stool's bacterial content, which may in turn reduce the risk of UTIs.

American Journal of Clinical Nutrition 2003;77:600-604.

<http://www.medscape.com/viewarticle/450477>

Richard's Pomade

½ cup coconut oil

2 capsules vitamin E

1 tablespoon jojoba oil

1 tablespoon favorite fragrance

1 tablespoon apricot oil, flower or herb essence

Blend for 15 seconds. If mixture is too “wet,” allow to chill in refrigerator. It will harden slightly. Keep in

refrigerator. Start off with about a tsp. of pomade, apply evenly through your hair. (You can always add more if you need it.)

Smelling Good May Cost Too Much

Smelling manly could harm more desirable manly traits, say some Harvard researchers.

Investigators at the university's School of Public Health have found a link between sperm damage and monoethyl phthalate (MEP), a compound used to maintain the color and scent in many cosmetic and personal care items such as perfumes, aftershave colognes, and hair spray.

In ongoing research, five different urinary phthalate metabolites were measured in semen and urine taken from 168 men, but only MEP yielded a significant association with affected sperm. Susan Duty, a postdoctoral research fellow, says that sperm defects were assessed from the length of a sperm's comet tail, which is formed in cells with damaged DNA—the longer the tail, the more problems there are. Prior studies have shown phthalates to be a reproductive toxin in rats.

Researchers are not certain why MEP is deleterious to sperm, so Duty and Russ Hauser, assistant professor of occupational and environmental health, are recruiting a much larger sample size for the next study. Until then, keep the deodorant and perfume in the medicine cabinet, Duty advises. “We can't make any recommendations at this time on such a small sample size.”

—Hal Cohen

www.freeimages.co.uk

Hashimoto's Disease and H.E. in a Nutshell

“Hashimoto's Disease” is one of several autoimmune diseases. Dr. Hakaru Hashimoto discovered the disease in 1912. The B cells of the immune system produce antibodies that seek and destroy thyroid cells. Sometimes it results in goiter (enlarged/inflamed thyroid). Most often it accompanies hypothyroiditis (not enough hormone) There is no cure known though it has been documented as going into remission or reverse itself into a hyperthyroid state. It is treated by mitigating the damage - i.e. replace thyroid hormone that is too low as a result of the disease process.

As with autoimmune disease in general, there is no known cause. The body is attacking itself literally. There are flareups that are sometimes treated with prednasone - much like other autoimmune diseases that

have flare ups are treated (MS, Lupus, Polymyalgia). The steroids help to inhibit the entire immune system including the antibodies wrongly programmed to attack one's own tissue. The steroids work to calm things down and then are tapered off slowly or maintained at a low dose to prevent flareups.

Hashimoto's disease includes symptoms common to all low thyroid states. These include: cold intolerance, heat intolerance, excessive sweating, unexplained weight gain, joint pain, muscle/tendon pain, nerve pain, headache, fatigue, insomnia, difficulty swallowing, regular, subnormal body temperature, constipation, excessive hair loss, excessively dry skin, brittle and cracking nails, Concentration Problems, Attention Span Problems, Cognitive Difficulties, Difficulty Retaining Information, Confusion, Short Term Memory Problems, Aphasia/Speech Difficulties, and often mild to moderate depression.

The symptoms could be caused by any number of things. Various infections, anemia, head injury, stress, drug reaction, any number of illness, disease, injury, other syndromes. One must check and rule out what is NOT causing it. The key to the diagnosis is very elevated antithyroid globulins that show an autoimmune processes attacking the thyroid gland and causing hypothyroidism.

Hashimoto's Encephalopathy (HE) is a rare autoimmune neuroendocrine disease that has been found in some patients with Hashimoto's Thyroiditis. Along with attacking thyroid cells, the antithyroid antibodies ALSO destroy neurons in the brain. Again the cause is unknown and the disease is underdiagnosed.

The common symptom list (what to watch for) - if someone is dx'd with Hashimoto's Disease AND has some of these difficulties, indicates a need for an extensive workup to see if HE is also a problem:

- * Attention Span Problems
- * Concentration Problems
- * Coordination Difficulties
- * Confusion
- * Headaches
- * Convulsions
- * Cognitive Difficulties
- * Coma
- * Difficulty Retaining Information
- * Dementia
- * Disorientation
- * Episodes of Stroke
- * Fatigue
- * Hallucinations
- * Psychosis
- * Short Term Memory Problems
- * Seizure Activity
- * Tremors
- * Word Finding Difficulties
- * Myoclonus - Rapid, Involuntary, Uncontrollable Muscle Jerks or Spasms
- * Fine Motor Movement Problems - Coordination of Arms, Hands, Fingers.
- * Episodes of Stroke-Like Deterioration
- * Right Sided Partial Paralysis
- * Left Sided Partial Paralysis
- * Aphasia/Speech Difficulties
- * Articulation Difficulties

(Gee, doesn't this list sound familiar?) If a person has Hashimoto's disease and many of these symptoms, a neurological workup is in order to see if HE is present. HE must be treated in a timely manner as the damage cannot be reversed. The workup for HE is painful, extensive and expensive. Not all neurologists are familiar with it. The best ones are those familiar with MS, Lupus and other autoimmune illnesses that have a neuroendocrine involvement. It includes a spinal tap, MRI, EEG, CT scans and more.

HE is considered a neuroendocrine disease because the antithyroid globulins attack the thyroid, but they also attack the neurons in the brain. Life management is a daytimer, post it notes, requests for reminder phone calls and a very patient and helpful caretaker. Find a neuro person who knows what HE is and will do the workup for it.

The good news is if the underlying hypothyroidism is treated and the HE is treated, a person will not have much trouble — generally. If it is HE, it needs to be diagnosed and treatment started ASAP, because left untreated for long it can cause irreversible damage. Treatment for HE is replacement thyroid hormones, steroids as needed to halt destruction of brain cells, and iv. gamma globulin.

Hashimoto's is actually pretty common in people with CFS. The symptoms can be successfully abated by the right thyroid drug or combination of thyroid drugs. Over time recognizing the signs of the hormones shifting becomes easier as some of the symptoms return. Other hormone problems, such as too little DHEA or estrogen, can cause symptoms very similar to those of untreated/under-treated Hashimoto's and other hypothyroid disorders.

There is an article recently, linked to Mary Shoman's thyroid site (<http://thyroid.about.com>), that said the endocrinology association recently lowered their "normal" level of one of the hormones used to decide whether the patient is hypothyroid or not. This immediately put several million Americans into the hypothyroid category who had previously been diagnosed as having normal thyroid function.

So, once one is being properly treated with the necessary hormone(s), a lot of the symptoms will disappear or at least be greatly mitigated. Some may continue, but they may be caused by something else. For example, Many of these symptoms are also commonly found in CFS, FM, late Lyme and chronic Myofascial pain. If some other disorders are going on, you may still be left with the symptoms.

Some links:

Hashimoto's Thyroiditis

<http://www.thyroidmanager.org/Chapter8/8-frame.htm>

Autoimmunity to the Thyroid Gland

(good overall explanation of immune system/function with diagrams also)

<http://www.thyroidmanager.org/Chapter7/7-text.htm>

Adult Hypothyroidism

<http://www.thyroidmanager.org/Chapter9/9-frame.htm>

Hashimoto's Encephalopathy: A Neuroendocrine Disorder

<http://www.thyroid-info.com/hashimotos-encephalopathy.htm>

HELPS - Hashimoto's Encephalopathy Loved Ones and Patients Support Group

<http://www.thyroid-info.com/helps.htm>

HE FAQ <http://www.thyroid-info.com/helpsfaq.htm#3>

Page 9

C. Pulmoni

Larry Klapow, Ph.D., has found what he believes is a new species of chronic roundworm parasite, *Cryptostrongylus pulmoni*, in a high percentage of CFS patients. Dr. Klapow is currently working on a diagnostic DNA test for *C. pulmoni*. Currently, the only way to detect the organism is through the microscope. Identification is difficult due to the extreme rarity, small size (200-950 microns), and decayed state of the specimens. Typically only one identifiable specimen per 3-day sputum collection was found.

The cause of the complex multi-systemic disease, variously known as Chronic Fatigue Syndrome (CFS) or Myalgic Encephalopathy (ME), remains unknown. Its sudden onset with infectious type symptoms in many patients, occurrence in outbreak-clusters, and near simultaneous appearance in "Western" countries in the mid-1980's, suggested the possibility of a rapidly dispersed primary infectious agent. *Cryptostrongylus pulmoni* was found to have infected 63% (14 out of 30) CDC-defined CFS patients, but not 21 controls. Since that is not all the patients, other factors may also be at work. Whether it is a cause or a coinfection must also be studied.

Roundworms in animals can produce many of the abnormalities seen in CFS, including auto-immunity, low serum cortisone, disrupted cardiovascular reflexes, altered anti-viral responses, respiratory and bowel symptoms, opportunistic infections, and mood and memory problems.

Roundworms secrete neuropeptides and cytokines. These active peptides appear to affect immunity and produce symptoms like those seen in CFS. Some species deplete serotonin. Another species secretes a substance resembling HCNP (hippocampal cholinergic stimulatory peptide) which occurs in areas of the brain involved in mood, memory, and very likely immunity.

Because chronic roundworm species often migrate through the lungs, sputum samples were examined during the trial. A few specimens of what appeared to be a new species of extremely small strongylid nematode (i.e., roundworm) were found, and assigned the provisional name *Cryptostrongylus pulmoni*, or "hidden lung worm".

Cryptostrongylus pulmoni is significantly associated with the syndrome and appears to have chronic properties. Specialized, inexpensive and simple imaging techniques are needed for positive identification.

Patients were from the CFS clinic at Brigham and Women's Hospital (Harvard Medical School), and from three primary care practices.

Sources:

Lawrence A. Klapow PhD, *Journal of Chronic Fatigue Syndrome*, 1999 5(3/4): 247-248

<http://www.anapsid.org/cnd/diffdx/klapow.html>

L. A. Klapow

Klapow Bioscience

Santa Rosa CA 95405, USA

e-mail: larryklapow@earthlink.net

Page 10

Alternative Meanings

Coffee (n.), a person who is coughed upon.

Flabbergasted (adj.), appalled over how much weight you have gained.

Abdicate (v.), to give up all hope of ever having a flat stomach.

Willy-nilly (adj.), impotent.

Negligent (adj.), describes a condition in which you absentmindedly answer the door in your nightie.

Lymph (v.), to walk with a lisp.

Gargoyle (n.), an olive flavored mouthwash.

Flatulence (n.) the emergency vehicle that picks you up after you are run over by a steamroller.

Balderdash (n.), a rapidly receding hairline.

Testicle (n.), a humorous question on an exam.

Rectitude (n.), the formal, dignified demeanor assumed by a proctologist immediately before he examines you.

Circumvent (n.), the opening in the front of boxer shorts.

Frisbeetarianism (n.), the belief that, when you die, your soul goes up on the roof and gets stuck there.

Pokemon (n), A Jamaican proctologist.

HELP!

How do you get through the day? Share your tips with the group by sending them to the newsletter.

Many of us find release in humor. Others turn to art for intellectual stimulus and an outlet for their creativity.

How do you cope?

Second Hand Smoke

February 10, 2003

from THE PRESS DEMOCRAT

Introduced Jan. 28 in the state Assembly, a bill by Joe Nation would allow residents in multifamily dwellings to sue their neighbors over secondhand smoke if it drifts in from their neighbor's homes. Said Nation, "I believe that people have a right to breathe clean air in their own homes."

By making tobacco illegal in one of the few havens left for smokers, the law may be hard to enforce. Instead of neighbors working things out by themselves, it could create a legal nightmare.

Nation's bill would declare tobacco smoke a public nuisance in apartments and condominiums. It would also ban smoking in indoor and outdoor common areas in apartment and condominium complexes, and require landlords to designate smoking and nonsmoking units by 2006.

Nation estimates that several thousand people are affected by their neighbors' secondhand smoke. For people with asthma or chronic lung disease, secondhand smoke can pose a serious health risk if smoke seeps into their apartment.

Nation also sponsored a bill that would raise the smoking age from 18 to 21, which would give California the highest legal smoking age in the country. The smoking age is 18 in 47 states. It is 19 in Alabama, Alaska and Utah. This could discourage young adults from lighting up and getting addicted to nicotine. Nation's website: <http://democrats.assembly.ca.gov/members/a06/>

Page 11

SARS

The number of people in the United States who might have contracted severe acute respiratory syndrome (SARS), a mysterious and deadly global respiratory illness, is unknown. But those infected here seem to be more resilient. CDC director Dr. Julie Gerberding announced. The virus spreads rapidly but may disappear just as quickly.

The mystery virus (SARS) may be a new paramyxovirus, one of several new diseases where a virus jumps species from animal to human. Other diseases in the same family are measles, mumps,

respiratory syncytial virus, canine distemper and colds.

The virus is a single-stranded RNA. It is roughly spirical (coronavirus) and appears to have a distinct herringbone pattern. The etiology is still in question. Several viruses in this group have recently been found jumping from animals to humans.

In 1995, (Hendra) from fruit bats, caused serious respiratory disease in Australia. In 1998 in Australia, Menangle virus from pigs caused influenza. In 2000 Nipah virus (from pigs) caused severe encephalitis in Malaysia and Singapore killed 105 people. Another member of the family is the new paramyxovirus virus, subfamily pneumovirinae, called metapneumovirus.

A CDC official said the search for the cause of SARS continues with no end in sight. Scientists have been working around the clock to understand the illness, which has now stricken people on four continents.

According to wire reports, a lab in Germany has isolated a paramyxovirus in specimens taken from a Singapore surgeon, his mother-in-law and his wife, confirmed as SARS cases. So far lab technicians "have looked at a broad range of bacterial and viral pathogens and have a lot of negative results, and a lot of studies are still in progress." One researcher in California using a new, quicker test he developed, confirmed the coronavirus category, but said it was definitely a new type.

Some of those infected by SARS have low white blood cell and platelet counts, which might provide another clue to why SARS is so deadly.

The CDC news conference last month in New York City was intended to announce the release of a new Institute of Medicine (IOM) report titled, "Microbial Threats to Health: Emergence, Detection, and Response." That calls on the United States to help beef up the world's capacity to track and respond to infectious diseases. A Singapore surgeon at that conference was hospitalized with SARS on his way home.

Another IOM document released in 1992 highlighted complacency about infectious diseases in the United States and other developed countries. The original report came just months before three major outbreaks of infectious pathogens. The timing of the new report and the outbreak seem bizarre.

The committee urged us all to continue to expect the unexpected. SARS reinforces the need for continued surveillance, the reinstatement of quarantine practices, and the need for sophisticated diagnostic laboratories. It reminds us that we need a better capacity to obtain diagnostic specimens from faraway places where diseases often appear. SARS is just the latest wake-up call.

Page 12

Biofeedback for Better Immune System Functioning

Peter Behel (Pain Management Clinic @ St. Helena Hospital,

23 years experience with biofeedback and stress management, works in Santa Rosa and Marin)

Biofeedback is useful in chronic pain management. The Art and Science of influencing and regulating the nervous system, it is a method whereby the patient takes an active part in their own medical care. It is a treatment, not a cure. It trains the patient to correct imbalances in the CNS/ANS and others systems.

Apparently current studies are beginning to find the connections between the Immune System, the Endocrine System and the Autonomic Nervous System. The hypothalamus seems to be the relay station where these systems interact. It balances the sympathetic (contractive) and parasympathetic (expansive) channels. All vital organs, glands and muscles are affected.

When there is an imbalance some systems are overstimulated and others are underutilized. This if continued over time creates a chronic condition and results in a disorder or impairment of the system. For instance, muscles overused and in a state of contraction become clenched, sore, tense and then freeze up creating loss of function and pain. The state of chronic tightness can also produce or worsen conditions like tension headache or TMJ.

Biofeedback uses a computer to display information so a person can learn to control some of the functions of the nervous system. A person can learn to relax enough to give the system a rest. Given enough practice, this breaks the cycle of adrenaline and allows a new balance to be created.

The effect of biofeedback on immune based conditions whether internally caused or produced by a pathogen is under study. But it is possible theoretically to influence that system with this approach. It is possible that sensitized people (like chronic sufferers) have moved through a progression of stages and are now constantly "on guard". Some relaxation techniques certainly wouldn't hurt. Of course, that is not like

saying that ours are self-inflicted illnesses or "all in your head".

Sugar and Memory

Poor glucose tolerance and memory deficits, short of dementia, often accompanies aging and smaller hippocampal volumes. In a small study 30 subjects were evaluated consecutively in an outpatient research setting. Glucose tolerance was measured. Memory was tested. The hippocampus and other brain volumes were measured.

Decreased peripheral glucose regulation was associated with decreased general cognitive performance, memory impairments, and atrophy of the hippocampus, a brain area that is key for learning and memory. These associations were independent of age and mental scores.

These data suggest an important mechanism for aging brain injury in elderly individuals with impaired glucose metabolism.

Center for Brain Health, New York University School of Medicine, 560 First Avenue, HN-400, New York, NY 10016.

E-mail: antonio.convit@med.nyu.edu.

www.pnas.org/cgi/doi/10.1073/pnas.0336073100

Tasty Hair Mousse

Ingredients:

2 egg whites

1 teaspoon rose or lavender fragrance

½ cup coconut oil

2 capsules vitamin E

Beat the egg whites until they form stiff peaks, then add other ingredients. Let set half an hour. Now apply sparingly and gently scrunch the ends.

Page 13

Sleep, Depression and Antidepressants

People with depression, a biochemical dysregulation that can be helped by taking antidepressants, "should" try them. If they are to help, one must give them enough time, and work with the prescribing physician/therapist to find the right drug, dose and time of day/night to take it.

As an adjunct to the medication, people with depression should also see a therapist, at least for the initial evaluation and maybe periodic checkins, since long-term untreated/undertreated depression can lead to behavioral patterns that are destructive rather than constructive and can counter the beneficial effects of medication. Taking medication only, without talk therapy, when such therapy is needed is like intentionally undermedicating yourself by taking only part of a dose or taking the drug half as often as prescribed.

When there is a biochemical imbalance or dysregulation that results in an undesirable symptom, such as not sleeping long enough or deep enough, definitely one should take whatever drug, if tolerated, that will help achieve the reduction or elimination of that symptom. No course of treatment will help much if you are only able to sleep 1-2 hrs a night. Sleep is tied into so much of our daily functioning, from behavior, memory, executive function, immune and endocrine function, and more, that sleep should be a priority on our hit list if we are having problem with it.

Also one must be sensitive to when the chemical tables have turned again, and the drug is no longer needed. Not all people need antidepressants all the time, for depression or for sleep. Biochemically, people are significantly different from each other and that difference can affect how other drugs are processed and how they act/react in the body. Bottom line is: we are all our own lab rats.

Melissa Kaplan

Flabbergasted: appalled over how much weight you've gained.

Tip: Family Support

Chronic illness is a family affair. Everyone whose life touches ours - our partners, children, parents, siblings, close friends - will be affected by our disease to a greater or lesser extent. They miss the person we used to be, and they aren't sure how to help us.

With the best of intentions, they may advise us to eat better, exercise more, and get back into the swing of life. Or worse, they may abandon us emotionally, refusing to acknowledge our struggles, or physically, deciding they can no longer bear the burden with us.

Communication on an individual level is always important, but sometimes patients need outside help to keep their relationships as healthy and intact as possible. Sometimes a group setting that encourages communication between partners is helpful; other times, it might be necessary to see a therapist one-on-one for the advice and support you need. Sometimes a Support Group like ours helps.

(Source: A Delicate Balance: Living Successfully with Chronic Illness, by Susan Milstrey Wells.)

Privacy Policy

The government has a new privacy policy in place to protect the confidentiality of your health records. No one may even know if you go to the hospital unless you ask to be included on their directory. This also means that someone else may not pick up your prescriptions without a signed consent from you. Finally, you have the right to all your medical records.