

The Carousel Network

Chronic Neuroimmune Diseases

Information & Support For Sonoma County

Chronic Fatigue Syndrome (CFS/CFIDS) • Fibromyalgia (FM)

Multiple Chemical Sensitivities (MCS) • Lyme Disease

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LETTER FROM THE EDITOR

Hello friends,

Looking around, there's no doubt that it's spring—everything is still green from the winter rains, and the flowers are all in bloom (although this is not a big plus to those of you who suffer from outdoor allergies)!

May brings with it *International CFS/FM/MCS/Lyme Disease Awareness Day* on May 12th. To honor that, we are participating in the *Million Letter Campaign*. Details can be found in the last newsletter. To be most effective, our letters should go out on or about May 1, so, if you haven't already done so, there's still time to send your letters.

We are also planning a special presentation at our May 7 TCN meeting. Dr. Lois Johnson, a local integrative and holistic CFS/FM/MCS/Lyme specialist, will outline her treatment protocols. Her presentation will be very informative, so come, bring your family and friends, and get your questions about your illnesses answered!

This issue of the newsletter includes the conclusion of an article summarizing diet & nutrition recommendations from prominent CFS/FM doctors (the first part appeared in the last issue), along with an article about the plastic containers we store our food and water in, and how the plastics may affect our health (and the environment).

I hope you enjoy this issue, and look forward to seeing you at the meeting on May 7!

Pat O'Hara

PLASTIC PLANET

Julie Rothschild Levi, February, 2005, *Delicious Living Magazine*

Peek inside any American household, and you'll find it brimming with plastics. From food containers, cling wraps, and water jugs to baby bottles and toys, plastics are ubiquitous because they're inexpensive, handy, and durable.

Yet many scientists and consumer advocates question the safety of plastics use. They argue that we're trading health for convenience. Others say ignore the hype—plastics are perfectly safe. Although several types of plastics do appear to be safe, some have been shown to potentially affect health, such as PVC (or vinyl), found in some cling wraps and toys, and polycarbonate (PC), found in baby bottles and tin-can linings.

From an environmental perspective, noxious chemicals from plastics manufacturing contribute to water, air, and soil pollution, affecting not only ecosystems but human health as well, especially in China and Mexico. And Americans recycle just 5 percent of all plastics—leaving the rest to sit in landfills forever.

Although it may not be necessary (or realistic) to purge plastics from our lives, it may well be worthwhile to consider reducing their use, for the sake of our health and our world.

How plastics affect your health

"We're reminded of the movie *The Graduate*, in which Dustin Hoffman was advised to go into plastics because it was the wave of the future," says Walter Crinnion, ND, head of the Environmental Medicine Center of Excellence at the Southwest College of Naturopathic Medicine and Health Sciences in Tempe, Arizona. "But what's happened is that plastics have gone into all of us."

Sounds scary, but how concerned should you be? That depends on whom you trust.

Scientists don't question the fact that chemicals migrate out of plastics. What they dispute is how it affects human health. "We're regulating [plastics], so they're safe," says Edward Machuga, PhD, a consumer safety officer at the Food and Drug Administration (FDA) in Washington, D.C. Manufacturers of any new food-contact plastic must conduct extensive tests and submit data to the FDA. The FDA sets limits on the levels of chemicals that plastics can release into food for humans, based on "acceptable dietary intake" levels shown to be nontoxic in animal studies.

That's not good enough anymore, says biologist Pete Myers, PhD, publisher of *EnvironmentalHealthNews.org* and coauthor of *Our Stolen Future* (Plume, 1997). "For decades the study of toxicology followed the paradigm that the dose makes the poison: High levels are bad, and low levels have no effect." But, he says, traditional studies miss a whole class of very low-level effects that can upset the hormonal system's natural balance.

The plastics to avoid, according to experts such as Myers, include PVC (recycle triangle number 3) and PC (recycle triangle number 7), which have been shown to leach out potentially hazardous chemicals. Of particular concern are phthalates, plasticizers added to many PVC products such as medical devices, toys, food wraps, cooking-oil bottles, and building products. A recent landmark study, conducted in part by the National Center for Environmental Health at the Centers for Disease Control and Prevention (CDC), detected seven common phthalates in the urine of all 289 subjects (*Environmental Health Perspectives*, 2000, vol. 108, no. 10). Such results support the

contention that phthalate exposure is both higher and more common than previously thought, says Crinnion.

Fetuses, young children, and women of reproductive age seem to be most vulnerable to these chemicals' effects. Phthalates have been found to be carcinogenic—and to cause fetal death, malformations, and reproductive toxicity—in laboratory animals (*Pediatrics*, 2003, vol. 111, no. 6). One recent study linked premature human births to maternal exposure to two phthalates, MEHP and DEHP, the most commonly used plasticizers (*Environmental Health Perspectives*, 2003, vol. 111, no. 14). Another showed that women with endometriosis had significantly higher-than-average DEHP concentrations in their blood (*Human Reproduction*, 2003, vol. 18, no. 7). And the CDC's 2000 study found significantly higher levels of MBHP, a proven reproductive and developmental toxicant in rodents, in its female subjects of reproductive age (20 to 40 years old).

However, a conflicting recent study concluded that DEHP and DINP phthalates are “not likely” to cause cancer in humans (*Critical Reviews in Toxicology*, 2003, vol. 33, no. 6). Also in 2003, the CDC issued a report stating that “median phthalate exposures” remain far below levels that could adversely affect humans.

Still, controversy continues, especially about soft plastic toys and teething rings, which usually are not labeled as containing PVC. Following a four-year scientific review, the U.S. Consumer Product Safety Commission recently declared PVC toys safe. The Toy Industry Association claims that generations of children have played with, and sucked on, toys made from pliable vinyl, with no evidence of adverse effects.

On the other hand, the environmental watchdog group Greenpeace has called on American toy manufacturers to phase out PVC plastic toys since 1996, and many companies have complied. (Their *Toy Report Card*, which grades major toy manufacturers on PVC use, can be found at www.greenpeaceusa.org.) In 1999, the European Union banned production of PVC teething toys for children 3 and younger, claiming they “present a serious and immediate risk to health.”

PC plastic—commonly found in food-can linings, baby bottles, 5-gallon water jugs, and Lexan (Nalgene) water bottles—may also be a health concern. Bisphenol-A (BPA), used in the production of PC plastics, is a known xenoestrogen (a compound that mimics estrogen in the body) and endocrine disrupter. BPA has been linked in mice with aneuploidy, a chromosomal abnormality causing spontaneous miscarriages, birth defects, and mental retardation (*Current Biology*, 2003, vol. 13, no. 7), as well as early puberty, prostate cancer, and reduced sperm count.

The American Plastics Council (APC) challenges such studies, on the basis that their relevance to human health has not been established. Claiming that BPA has been “safely used” for more than 40 years, the APC cites other research that has found no basis for health concerns from BPA exposure through PC products (*Toxicological Sciences*, 2002, vol. 68, nos. 121–146). (The cited study, however, used rodents and was largely sponsored by plastics manufacturers.)

As with PVC, several experts counsel avoiding PC altogether. To be safe, Myers advises using baby bottles made of glass or polyethylene and stainless-steel water bottles.

“The chemical industry is spending an incredible amount of money to convince us that their chemicals are totally safe and inert,” Crinnion says. “But we were told DDT,

formaldehyde, and vinyl chloride were safe and nontoxic. [The manufacturers] have not been proved correct once.”

Before you start tossing out your plastic collection, it’s important to note that not all plastics have been proven problematic. Most water bottles, as well as soda, juice, and sports-drink bottles, yogurt cartons, bread bags, boil-in-bag pouches, cereal-box liners, and food-storage bags (such as Ziploc) are examples of food-grade plastics with no known health hazards.

Most important, food-grade plastics must be used properly. “You want to use plastics for what they were intended for and approved for,” says the FDA’s Machuga. Heat, fat, and wear and tear all speed up the leaching process. So don’t microwave plastic that’s not specified for such use (such as margarine tubs) or put top-shelf-only plastic, such as children’s sippy cups and baby bottles, on the bottom shelf of a dishwasher. Remove cling wrap from any store-bought meats, cheeses, and fish. And if a plastic container starts to look cloudy or gets scratched up, toss or recycle it.

How plastics affect the environment

It’s hard to miss the “Made in China” stamp on the countless plastics products sold in the United States. Most plastics are produced today in countries such as China and Mexico because of lower production costs and looser environmental restrictions. “Countries [like China] suffer the highest rate of environmental degradation on the planet,” says Gabriel Filippelli, PhD, professor and chair of the department of geology studies at Indiana University-Purdue University in Indianapolis.

The petroleum-based solvents used to make plastics don’t hurt just fish and plants—they affect humans as well. Tens of millions of Mexicans and Chinese ingest solvent-riddled waters, Filippelli notes, while workers in plastics factories breathe noxious fumes that hurt cells in the lung lining, increasing the risk of emphysema and cancer. A recent Israeli study linked occupational PVC exposure with headache, tingling of limbs, and sore eyes (*American Journal of Industrial Medicine*, 2001, vol. 40, no. 2).

In the United States, most workers are no longer exposed to toxic chemicals. However, says Filippelli, “many solvents in plastic-production facilities can easily leak from their source tanks into the subsurface, which can contaminate groundwater.”

Benzene, a common solvent and building block for plastics manufacture, can cause temporary nervous-system disorders, as well as long-term chromosomal aberrations and cancer, according to the Environmental Protection Agency. (In 1995, the EPA required all water suppliers to collect and analyze water samples regularly for benzene levels above the limit.)

Although gasoline and pesticides are major groundwater contaminants, Filippelli says that plastics are “equally problematic.” In 1992, the industry produced 567 million pounds of toxic waste, according to the EPA. That same year, companies put about 25 percent of their total waste back into the environment.

Most American cities have some groundwater contamination due to solvent leakages. The U.S. National Research Council estimates that costs of cleaning up the known 300,000 to 400,000 heavily contaminated groundwater sites could be as high as \$1 trillion over the next 30 years.

Plastics and your landfill

Beyond the risks and costs associated with making and using plastics, there is another challenge: trying to dispose of mountains of nonbiodegradable material. Plastics

take up 25 percent of landfill space in the United States. Although many are easily compacted, “plastics will persist in landfills for easily anywhere from 10,000 to 100,000 years,” says Filippelli.

Thankfully, biodegradable plastic alternatives are being developed around the world. Starch-based biodegradable plastics, for instance, take only a few weeks to a few months to dissolve in composting facilities. Santa Barbara, California-based EarthShell Corporation provides biodegradable packaging to McDonald’s restaurants and markets biodegradable sandwich wraps made from limestone and potato starch. Wild Oats natural foods stores are pioneering the use of Cargill Dow’s biodegradable, clear plastic deli containers, based mainly on corn-derived polylactic acid. (For optimal results, most customers return the containers to stores for composting.) And recently, Irish scientists discovered a bacterial strain that detoxifies styrene, a toxic by-product found in Styrofoam, and turns it into a safe, biodegradable product; they are conducting pilot-scale fermentations and exploring large-scale applications.

Recycling plastics can help cut down on waste, too. If every American household recycled just 1 of 10 HDPE (number 2) bottles used, it would keep 200 million pounds of plastics out of landfills annually. Recycled plastics are used for fleece clothing, luggage, garden hoses, egg cartons, and dozens of other products. Most major urban areas have programs for PETE and HDPE (numbers 1 and 2), the most commonly recycled plastics. Yet in 2002, Americans recycled just 21 percent of their plastic beverage bottles.

Many experts agree that the best way to diminish these unfavorable effects is simply to cut down on plastics’ use. Glass and ceramic make safe storage containers; waxed-paper sheets and bags, as well as parchment paper, are alternatives to plastic wraps and bags. “There are so many exposures to plastics that we can’t control,” says Crinnion, “but what’s in the air of your home and in the food you choose to buy and eat is in your control.”

DIET & NUTRITIONAL SUPPLEMENT RECOMMENDATIONS FROM LEADING FIBROMYALGIA AND CHRONIC FATIGUE SYNDROME PHYSICIANS—PART 2

Lee Ann Stiff, www.ImmuneSupport.com, January 23, 2004

[Ed: This is the conclusion of an article from the previous issue of the newsletter. This article presents dietary and nutritional supplementation advice from several prominent Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM) doctors.]

PAUL CHENEY, M.D.

Paul Cheney, M.D., Ph.D., is one of the most recognized names in CFS treatment and research. He has treated over 3,000 patients with CFS from 48 states and 15 countries. Dr. Cheney has published numerous articles in peer reviewed medical journals, and has lectured around the world. He was a founding Director of the American Association of Chronic Fatigue Syndrome (AACFS), a professional association of scientists and clinicians. Dr. Cheney’s Web site is <http://www.fnmedcenter.com/ccis/>.

Basic diet recommendations

No sugar: Due to defects in utilization, it produces toxins that cause pain, headaches and neuropsychiatric problems. Sugar stimulates the growth of abnormal gut microflora, especially Candida (yeast). It generates a tremendous amount of free

radicals and raises insulin levels, both of which are very problematic for patients. If you crave it, try eating carbohydrates instead. If you must, eat sugar (including fruit) with meals, never by itself. Some honey and powdered fructose can be used in cooking, as well as the herbal sweetener stevia.

Reduce "bad" fat: Limit daily intake to less than 30 grams due to a defect in fat transport across mitochondrial membranes that is seen in patients. Supplementation, however, of essential fats (EFA's omega-3 and omega-6) is necessary.

No Nutrasweet: This artificial sugar substitute contains the toxin methanol and can exacerbate neurotoxicity.

No red meat: High in the bad kind of fat and difficult to digest, it causes gastrointestinal (GI) tract symptoms and systemic symptoms such as joint pain.

No caffeine: Or at least limit your intake as much as possible.

Be careful with the following: Eliminate them entirely or try two separate three-week programs of off/on/off these foods, and note if symptoms improve in the off week.

Dairy products (can cause GI and systemic symptoms); **Gluten** (can cause GI and systemic symptoms) which is found in wheat and oats, and thus in cereal, bread and pasta. [Ed: *Gluten is also found in barley and rye.*] Gluten-free products are available.

PAUL ST. AMAND, M.D.

Paul St. Amand, M.D., Assistant Clinical Professor of Endocrinology at Harbor-UCLA (for the past 45 years), believes guaifenesin therapy can significantly help FM patients combat their symptoms and lead normal, healthy lives. Dr. St. Amand is also in private medical practice in Marina del Rey, California, and is the co-author of "What Your Doctor May Not Tell You About Fibromyalgia."

Dr. Paul St. Amand's theory of the medicinal effects of guaifenesin for FM is based on the premise that excess calcium and inorganic phosphate compounds accumulate within cells to produce a state of hyperpermeability. This condition allows excess fluids, ions and other unwanted substances to flow into cell mitochondria, disrupting normal cell function, including production of ATP, the body's energy source. Dr. St. Amand believes these factors cause the body to experience an energy-deprived state, in which widespread bodily functions are disrupted. Dr. St. Amand also feels a possible genetic defect in FM patients may be responsible for the abnormality in natural phosphate excretion, thus resulting in the buildup of these chemicals and subsequent symptoms.

What is guaifenesin? Guaifenesin is a common component of many cold and cough remedies that helps loosen and liquefy mucous. It is a safe medication that may even be used by children. Derived from a tree bark extract called guaiacum, it was first used to treat rheumatism during the 16th century. Twenty years ago, the extract was synthesized, pressed into tablets and named guaifenesin. Today, there are many formulations of guaifenesin available, the most popular being extended release tablets that deliver both immediate and long lasting effects.

The St. Amand Guaifenesin Protocol: Guaifenesin is regarded by Dr. St. Amand as the most potent drug to date for treating FM. In Dr. St. Amand's guaifenesin protocol, a physician maps the location, size and degree of hardness of swellings or lesions within muscles, tendons and ligaments all across the body. The map serves as a baseline for future comparisons during guaifenesin treatment. Patients also make note of variations in the amount of pain and fatigue they experience, and the combined input is used to determine the proper guaifenesin dosage and to confirm the regression of the disease.

The initial goal of guaifenesin treatment is to exacerbate the patient's symptoms. Dr. St. Amand stresses that the worsening of FM symptoms, or the appearance of new symptoms indicates that disease reversal has begun. Dosage generally begins with 300mg (one-half tablet) of time released guaifenesin twice daily for one week. If symptoms have not worsened, the dosage is increased to 600mg twice daily. As treatment continues and the reversal process progresses, periods of less intense symptoms appear.

As time passes, these periods cluster into days and weeks and lesions begin to clear. He has also reported a 60% increase in phosphate excretion and a 30% increase in oxalate in patients' urine, indicating that the offending compounds are effectively being removed from the body.

Salicylates: An important part of Dr. St. Amand's protocol focuses on the avoidance of salicylates. In nature, salicylates are manufactured by plants as a defense against bacteria and fungi. Aspirin and other herbal or plant based products contain salicylates or salicylic acid. Any product containing salicylates can completely block the benefits of guaifenesin. The human body easily absorbs salicylates through the skin and intestines, so patients taking guaifenesin must be wary of medicines, supplements, lotions, cosmetics and even garden plants which can neutralize guaifenesin treatment.

HARRIS MCLLWAIN, M.D.

Harris McIlwain, M.D., C.M.D. is a rheumatologist, geriatric medical specialist, and founder of the Tampa Medical Group in Florida, and has been in medical practice for twenty-five years. The Tampa Medical Group has four physicians who specialize in rheumatology and internal medicine. Dr. McIlwain and his colleagues see hundreds of patients each week, many suffering with FM syndrome. The revised third edition of Dr. McIlwain's popular book, "The Fibromyalgia Handbook: A 7-Step Program to Halt and Even Reverse Fibromyalgia" is now available (an Owl Book, published by Henry Holt and Company). The following is an excerpt from this book.

Follow the Nutritional Plan for Healing: Although there are no specific "magic" foods that are proven to cure FM, research has shown that there are some positive nutritional measures you can take to heal your body. Being at the proper weight and eating healthful foods, including those that are low in fat and high in immunity-boosting antioxidants and phytochemicals, work together to help maximize energy and alertness, while possibly minimizing the constant fatigue and lethargy that accompany this syndrome.

Maintaining health and feeling good becomes increasingly more complicated with chronic diseases like FM. Good health is more about the precise balance of a sound body, mind, and spirit than just the absence of disease. There are unique links among the brain, the hormone system, and the immune system. Within this balance, these links make feeling our best a total experience—physical, mental and emotional. Taking charge of the areas of your health that you can control helps to optimize how you feel even in the midst of the aches and fatigue of FM.

Taking control of your disease: Eating for wellness is one of the treatment areas that you do have control over. Knowing that you are doing all you can to eat healthily can give you a sense of power to sustain your physical needs and help you cope with the stresses of everyday life and FM. The food choices you make can affect your weight; obesity is a significant health problem in the United States as well as in other developed nations. Studies are now being conducted to see if obesity contributes to an impaired immune system.

Antioxidants give cell protection: Antioxidants are essential nutrients that help protect your body against life's stressors. Antioxidant food sources are rich in beta carotene and vitamins C and E. Antioxidants are thought to play a role in the body's cell-protection system and to interfere with aging and the disease process by neutralizing highly reactive and unstable molecules, called free radicals, produced by the body. In research, free radicals have been shown to disrupt and tear apart vital cell structures like cell membranes. Antioxidants have been shown to tie up these free radicals and take away their destructive power, perhaps reducing the risk of a number of chronic diseases and even slowing the aging process. Eating for wellness requires a diet rich in antioxidants.

Some researchers think that antioxidants might help prevent damage in some types of arthritis and boost immune function when a system is under stress. Both are important benefits for patients.

Understanding antioxidant food sources

Beta carotene: Found in apricots, carrots, cantaloupe, pumpkin, spinach, broccoli, collard greens, tomatoes, papayas and peaches (among other sources), is converted to vitamin A in the body. Because of a great deal of media attention, most people think of only beta carotene as having antioxidant properties, but there are many other carotenoid compounds that do also, including: alpha-carotene (found in carrots, cantaloupe, and pumpkin), gamma-carotene (found in apricots and tomatoes), beta-cryptoxanthin (found in mangoes, nectarines, peaches, and tangerines), lycopene (found in tomatoes, guava, pink grapefruit, and watermelon), lutein and zeaxanthin (found in beets, corn, collard and mustard greens).

Vitamin C (ascorbic acid): Protects us against infection and aids in wound healing. When the body is under great stress, the blood levels of ascorbic acid have been found to decline. This decline also occurs with age in both men and women. Vitamin C plays a vital role in boosting levels of the energizing brain chemical norepinephrine.

Norepinephrine: Produces a feeling of alertness and increases concentration. A deficiency of vitamin C can therefore influence your mood as well, leaving you less attentive. It is essential to include plenty of vitamin C sources in your diet (broccoli, oranges, cantaloupe, grapefruit, kiwi, peppers, potatoes, strawberries, tomatoes).

Vitamin E: Is important to the body for the maintenance of cell membranes, and this vitamin's antioxidant effect may slow age-related changes in the body. There is now evidence that vitamin E plays a role in lowering the risk of coronary heart disease and heart attack. Adults with intestinal disorders of malabsorption may be deficient in vitamin E. Because this vitamin is taken in through vegetables and seed oils, it is difficult to ingest large amounts, especially if you are on a low-fat diet. If your diet is low in vitamin E food sources, check with your doctor to see if you should add 200 to 400 IU daily through supplementation. Food sources of vitamin E include nuts and seeds, vegetable oil, and wheat germ.

Zinc to resist infection: Zinc also has antioxidant effects and is vital to the body's resistance to infection and for tissue repair. Many illnesses, such as some cancers, kidney disease, long-term infection, trauma, and cirrhosis of the liver, are associated with zinc deficiency.

Medications may also interfere with the absorption in the intestines and cause a zinc deficiency. More research infers that zinc can help to improve the immune system in elderly people. However, cautions must be raised as high doses of zinc are toxic and

may, in fact, suppress immune function. Again, check with your physician for what is safe in your situation. Foods high in zinc include seafood, eggs, meats, whole grains, wheat germ, nuts and seeds; tea and coffee may hinder absorption.

Magnesium to reduce pain: Magnesium is vital for healthy muscle metabolism and function. Yet, when you have a magnesium deficiency, you may experience excessive muscle tension, muscle spasms, restlessness, tics, and twitches. Studies now indicate that magnesium is particularly important for those with FM as it inhibits nerve receptors linked to the trigger point pain and regulates the release of neurohormones.

In a comprehensive study published in the journal *Alternative Medicine Alert* (March 2002), researchers found that just 500 milligrams of oral magnesium taken daily can significantly increase muscle magnesium level and influence FM symptoms. In another study published in the *Cochrane Database of Systematic Reviews* (2001), researchers found that magnesium supplementation can help to alleviate painful menstrual cramps, although they are unsure of the exact amount needed.

Because magnesium supplementation can cause gastrointestinal symptoms, including watery diarrhea, talk to your doctor first before trying this therapy. Foods high in magnesium include cereals, nuts, sunflower seeds, barley, quinoa, tofu, dairy products, bananas, pineapples, artichokes, avocados, lima beans, spinach, okra, hummus, oysters, mackerel, grouper, cod and sole.

B vitamins may ease your FM symptoms: There is strong indication that some foods high in the B vitamins help to alleviate some FM symptoms. For instance, folic acid, a B vitamin, seems to be a leader in mood management [*ImmuneSupport.com Editor's note: FM and Myofascial Pain Syndrome (MPS) researcher Devin Starlanyl has noted that folic acid is often in short supply in FM and MPS patients*].

In research performed at Massachusetts General Hospital in Boston and the Baylor Research Institute in Dallas, studies conclude that people with low folic acid levels are more likely to have melancholia, a type of depression characterized by sadness and declines in mental and physical activity. The eight-week study of 213 patients also found that those with low levels of folic acid were significantly less likely to respond to treatment for depression with fluoxetine (Prozac), a common antidepressant medication used for FM patients.

Vitamin B-12: Works closely with folic acid to make red blood cells and prevent anemia, memory loss, nerve damage, muscle weakness, and fatigue (if you are a vegetarian, getting ample vitamin B-12 is difficult, so talk to your doctor to see if supplementation is needed). Food sources of folic acid include green leafy vegetables, asparagus, cantaloupe, spinach, lima beans, kidney beans, pinto beans, navy beans, tofu, sweet potatoes, citrus fruits, and peanuts. Food sources of vitamin B-12 include eggs, dairy products, and oysters.

Choose plant-based phytochemicals: Nutrition research is now revealing that a variety of food choices can do more than provide optimal nutrient intake. A varied diet can also provide hundreds of nutrient and non-nutrient compounds that may be vital to protection from disease. These compounds found in plant-based foods as a group are referred to as phytochemicals.

Phytochemicals appear in all plants. A diet that includes a variety of grains, fruits, and vegetables should provide these substances if you vary your choices and methods of food preparation. Although there are phytochemical supplements and pills available, it is best to get your phytochemicals from a varied diet.

Other immune boosters

A great concern for anyone with a chronic illness is avoiding other illnesses. For example, FM can make you feel flu-like with the muscle aches and fatigue. So getting the flu on top of having FM is like a double whammy. What about those who have FM and also develop osteoporosis or heart disease? It doesn't have to happen to you, and one way to protect yourself from viruses, infections, and other chronic illnesses is to keep your immune system boosted so it can adequately fight to keep you well.

Flavonoids (or bioflavonoids): Include about 4,000 compounds that are responsible for the colors of fruits and flowers. Hosts of experiments on bioflavonoids found in the soft white skin of citrus fruits have suggested that these key nutrients increase immune system activation. These biochemically active substances accompany vitamin C in plants and act as an antioxidant. You can find bioflavonoids in grapefruit, oranges, lemons and limes. Rose hips, apricots, cherries, grapes, black currants, plums, blackberries, and papayas are other fruit sources of bioflavonoids. Green peppers, broccoli, eggplant, squash, and tomatoes are some good vegetable sources of bioflavonoids. Tea, red wine, and parsley are also good sources.

Quercetin: This is a very highly concentrated form of bioflavonoids that is found in citrus fruits, red and yellow onions, and broccoli. Quercetin reduces inflammation associated with allergies. Other citrus flavonoids include hesperidin, which is said to raise blood levels of the "good" high-density lipoprotein (HDL fats) and lower the "bad" low-density lipoprotein (LDL fats) and triglycerides, and tangeritin, which induces apoptosis, or programmed cell death, in leukemia cells, but does not harm normal cells.

Glutathione: Another nutrient that has been found to strengthen the immune system so it can fight other infections is glutathione. This powerful antioxidant is most plentiful in the red, pulpy area of the watermelon near the rind. It can also be found in cruciferous vegetables.

Natural dietary supplements

Dietary supplements include a host of products that contain vitamins, minerals, herbs and amino acids as well as natural enzymes, organ tissues, metabolites, extracts, or concentrates. Some alternative practitioners recommend the following natural remedies for prevention and treatment of disease.

Chromium picolinate is a trace mineral important in helping cells break down sugar into energy for the body. Supplements can help to regulate blood sugar, fat, and carbohydrate metabolism. Uncontrolled blood sugar levels can contribute to weight gain, high cholesterol, and high blood pressure. Interestingly, chromium seems to normalize low blood sugar. A recent USDA study of 180 Type 2 diabetics in China documented "spectacular" results from taking 1,000 micrograms of chromium picolinate daily. For those with FM, taking chromium may help in stabilizing mood swings and anxiety caused by fluctuation in blood sugar levels.

Coenzyme Q10 (CoQ10) is a natural substance that improves heart and immune function. It is also an antioxidant that helps to lower cholesterol levels and reduces oxidative damage to blood vessels.

Essential fatty acids (EFAs) are not manufactured by the body, but these fats are essential to cardiovascular health and normal brain development. EFAs are available in oils containing omega-3 (fish oils) and omega-6 (linolenic and gamma-linolenic, or GLA, which are found in plant oils such as evening primrose, black currant, and borage).

Glucosamine and chondroitin are two substances that the human body produces to make cartilage. In supplement form, glucosamine comes from crab shells, and chondroitin comes from cow cartilage. Although scientific studies have yet to call them the “cure” for arthritis, in some studies of people with arthritis, these supplements were found to ease aches as well as over-the-counter painkillers, but more slowly. Although their long-term safety has never been officially established, they appear to have no side effects, and researchers do not know whether you must take the two supplements together [for maximum benefits] or if one is effective taken all by itself. If you have osteoarthritis along with FM, this natural solution might help you.

Lecithin is commercially isolated from soybeans, corn, and eggs, and may help with easing the memory glitches that happen with aging. Just two tablespoons of lecithin a day stimulates the body’s output of choline, a brain chemical that is important to recall and memory.

Conclusion

Now that you’ve read about the approaches some of the leading practitioners recommend to help FM and CFS patients feel better through diet and nutritional supplementation, talk to your healthcare provider or a qualified nutritionist familiar with FM and CFS about the changes you’d like to make in your own life. Will your most aggravating symptoms lessen or disappear altogether through changing your diet? You’ll never know until you try, but chances are, making simple changes to your diet and addressing your nutritional deficiencies will make you feel a whole lot better—and will make your body stronger to continue on the road to wellness.

FROM THE NEWSWIRES

Help with prescription drug costs

Drug manufacturers, under fire from consumer advocacy groups for opposing legislation to reduce prescription costs, announced that they would spend about \$30 million through June to develop and promote a program that would help poor Americans gain access to the medicines they need. The new program establishes a Web site and call centers to match consumers with the program that best suits their needs.

"This is serious business. This is going to be very expensive for the companies, but they're willing to make this commitment to save the free-market system in America," said Billy Tauzin, a former House committee chairman who is now president and CEO of the Pharmaceutical Research and Manufacturers of America.

Consumers can access the Partnership for Prescription Assistance program by calling a toll free number (888-477-2669), or through the Internet at <http://www.pparx.org>.

Lane Labs refund

Due to a 2004 U.S. District Court decision in New Jersey, Lane Labs is being required to issue refunds to all purchasers of Benefin, MGN-3, and SkinAnswer. The court found that these products were unapproved new drugs under federal law because they were being marketed as treatments for cancer, HIV, and skin cancer without FDA approval.

MGN-3 was prescribed as an immune enhancer by many doctors treating CFS and FM. If you purchased MGN-3, or either of the other two Lane Labs products since

September 22, 1999, contact the FDA District Office in New Jersey (973-526-6000) or the TCN Newsletter Editor (707-324-8881 or newsletter@cndsinfo.net) for a refund form.

New FDA office of drug safety proposed

Senators Charles Grassley, R-Iowa, and Chris Dodd, D-Conn., recently proposed legislation to establish a new agency to monitor the safety of prescription drugs after they are approved for the market. The new independent office within the Food and Drug Administration (FDA) would have authority to pull any unsafe drug from the marketplace, under the bill. The office would have broad authority to require new studies, change labels and approve advertisements and marketing materials. The law also would require drug companies to make the results of their clinical trials public.

Under current law, the FDA has no authority to withdraw a drug once it's been approved, nor does it have the authority to require post-market studies. The FDA conducts extensive reviews of a new drug's usefulness and safety before approval, but has done little to monitor side effects that become apparent only with millions of applications.

Last September, Merck voluntarily pulled Vioxx from the market after studies showed increased risk of heart disease. Other drugs in the same class, such as Bextra, Celebrex and naproxen have also been linked to serious heart problems. Earlier this month, Pfizer voluntarily pulled Bextra from the market, citing safety concerns. At the same time, Pfizer said it would continue to market Celebrex.

Prescription drug safety tips

The Partnership for Safe Medicine, a U.S. national coalition of patient, doctor, pharmacist, industry and professional organizations, has released a guide for consumers containing safety tips to help determine when prescription drugs are effective and safe to use.

The "S.A.F.E. D.R.U.G." guide was released in response to the growing issue of fake or ineffective counterfeit drugs in the United States. The new guide offers advice to consumers on how to avoid, identify and report counterfeit drugs. These tips help people judge whether their medications are safe and what they should do if they feel a medication has been compromised.

The guide can be found on the Internet at <http://www.safemedicines.org>, or you can obtain a copy by contacting the TCN Newsletter Editor.

Recall of Kingswood Laboratories Moi-Stir Oral Swabsticks due to contamination with molds

Kingswood Laboratories and the FDA notified healthcare professionals of a nationwide recall of Moi-Stir Oral Swabsticks due to the finding that certain lots contain molds, including *Aspergillus* and *Penicillium*, which could result in respiratory infections. The swabsticks contain a saliva supplement intended to relieve dry mouth, physically clean the oral cavity, thin phlegm, and lower dental caries rates. The product was distributed to hospitals, hospital wholesalers, pharmacies, nursing homes, physician and dentist offices, consumers, some government medical facilities, and as free samples to a

small number of individuals. Doctors and dentists should consider screening patients who are at risk for infections, especially those with weakened immune systems (low white blood cell counts) who have used the Moi-Stir Swabstick.

Read the complete MedWatch 2005 Safety Summary, including a link to the firm press release, at <http://www.fda.gov/medwatch/SAFETY/2005/safety05.htm#MoiStir>.

“Best Doctors” list

San Francisco magazine reports the results of a bi-annual poll by Best Doctors, Inc. The Boston-based company polls doctors to find out who they would recommend to family and friends in need of a specialist. Seven Sonoma County physicians made the list of 520 Bay Area doctors. They are:

- Dr. Marshall Kubota, AIDS expert
- Dr. Richard Auld, Gastroenterology Associates
- Dr. Dale Westrom, Dermatology Associates
- Dr. John M. Gray, orthopedic surgeon and spine specialist
- Dr. Richard Permutt, Kaiser, gastroenterologist
- Dr. Thomas Cory, Kaiser, pediatric specialist
- Dr. Mindy Shaprio, Kaiser, pulmonary and critical care medicine

FROM JERRY’S DESK

Don't forget the *Million Letter Campaign*. If you have, go back to the last newsletter for info and addresses. It's not too late to send your letters. This is probably the best chance that I have seen to be heard concerning our illnesses. Let's join with others all across the country to "make a difference."

Our speaker for the May 7th meeting is Dr. Lois Johnson. She is a "Holistic-Integrative Physician/Herbalist" here in Santa Rosa. She has been treating our illnesses for many years, and prefers to start with a more natural-herbal, less toxic approach, whenever possible. I also just discovered that she is treating Lyme disease.

As I said at the April meeting, please feel free to bring friends and family. There is nothing like a room full of people with the same illnesses, and a great speaker like Dr. Johnson, to get through to them that you are really sick. See you all on May 7th.

- Jerry Sundahl

RESEARCH BRIEFS

Additional information about these research papers can be found on the Internet at <http://www.pubmed.org>, or by contacting the TCN Editor at (707) 324-8881, or newsletter@cndsinfo.net.

Genetic factors in neuromuscular pain.

Buskila D, Neumann L, Press J.; Department of Internal Medicine, Faculty of Health Sciences, Ben Gurion University of the Negev, Beer Sheva, Israel.
CNS Spectr. 2005 Apr;10(4):281-4.

ABSTRACT: Recent evidence suggests that fibromyalgia, a chronic widespread pain condition and related syndromes (chronic fatigue syndrome, irritable bowel syndrome,

etc.) may share heritable pathophysiologic features. We review the recent literature on genetic and familial factors found to participate in the pathogenesis of these syndromes, specifically fibromyalgia, including evidence suggesting that serotonin- and dopamine-related genes may play a role in the pathogenesis of these illnesses. The importance of environmental factors triggering these conditions in predisposed individuals is also discussed.

Serum growth hormone and insulin but not insulin-like growth factor-1 levels are elevated in patients with fibromyalgia syndrome.

Denko CW, Malemud CJ.; Department of Medicine, Division of Rheumatic Diseases, Case Western Reserve University School of Medicine, Cleveland, Ohio, USA.
Rheumatol Int. 2005 Mar;25(2):146-51.

ABSTRACT: Standard radioimmunoassay (RIA) was employed to quantify basal serum growth hormone (GH), insulin-like growth factor-I (IGF-1), and insulin levels in 32 normoglycemic patients with clinically active fibromyalgia and in 29 normoglycemic control subjects. The GH concentration was significantly higher ($P < 0.001$) in female fibromyalgia patients than age-matched, normal female subjects. In contrast, basal serum IGF-1 concentrations did not differ between these groups. A scatter plot generated from two-stage, least-squares analysis showed that serum GH lacked correlation with the serum IGF-1 concentrations of normal female subjects ($P = 0.73$) and female fibromyalgia patients ($P = 0.19$). In addition to the results from serum GH and IGF-1 RIA, we also found significantly higher fasting serum insulin levels ($P = 0.03$) in male fibromyalgia patients and a trend toward elevated fasting serum insulin levels in the female fibromyalgia population ($P = 0.07$), with the mean fasting level in the male fibromyalgia group ($35.7 \mu\text{U/ml}(-1)$) exceeding the upper limit of normal serum insulin levels (i.e., $27 \mu\text{U/ml}(-1)$). Based on these results, basal serum GH and fasting serum insulin levels appear to be valuable surrogate markers in clinically active, normoglycemic fibromyalgia patients.

Exercise responsive genes measured in peripheral blood of women with chronic fatigue syndrome and matched control subjects.

Whistler T, Jones JF, Unger ER, Vernon SD.; Viral Exanthems and Herpesvirus Branch, Centers for Disease Control and Prevention, Atlanta, GA 30333, USA.
BMC Physiol. 2005 Mar 24;5(1):5.

BACKGROUND: Chronic fatigue syndrome (CFS) is defined by debilitating fatigue that is exacerbated by physical or mental exertion. To search for markers of CFS-associated post-exertional fatigue, we measured peripheral blood gene expression profiles of women with CFS and matched controls before and after exercise challenge. RESULTS: Women with CFS and healthy, age-matched, sedentary controls were exercised on a stationary bicycle at 70% of their predicted maximum workload. Blood was obtained before and after the challenge, total RNA was extracted from mononuclear cells, and signal intensity of the labeled cDNA hybridized to a 3800-gene oligonucleotide microarray was measured. We identified differences in gene expression among and between subject groups before and after exercise challenge and evaluated differences in terms of Gene Ontology categories. Exercise-responsive genes differed between CFS patients and controls. These were in genes classified in chromatin and nucleosome assembly, cytoplasmic vesicles, membrane transport, and G protein-coupled receptor ontologies. Differences in ion transport and ion channel activity were evident at baseline and were exaggerated after exercise, as evidenced by greater numbers of differentially expressed genes in these molecular functions. CONCLUSION: These results highlight

the potential use of an exercise challenge combined with microarray gene expression analysis in identifying gene ontologies associated with CFS.

The role of *Borrelia burgdorferi* in interstitial cystitis.

Haarala M, Kiiholma P, Nurmi M, Uksila J, Alanen A.; Obstetrics and Gynecology, University of Turku, Finland.

Eur Urol. 2000 Apr;37(4):395-9.

In vitro susceptibility testing of *Borrelia burgdorferi sensu lato* isolates cultured from patients with erythema migrans before and after antimicrobial chemotherapy.

Hunfeldt KP, Ruzic-Sabljić E, Norris DE, Kraiczky P, Strle F.; Institute of Medical Microbiology, University Hospital of Frankfurt, Paul-Ehrlich Str. 40, D-60596 Frankfurt/Main, Germany.

Antimicrob Agents Chemother. 2005 Apr;49(4):1294-301.

Pregabalin for the treatment of fibromyalgia syndrome: results of a randomized, double-blind, placebo-controlled trial.

Crofford LJ, Rowbotham MC, Mease PJ, Russell IJ, Dworkin RH, Corbin AE, Young JP Jr, LaMoreaux LK, Martin SA, Sharma U; Pregabalin 1008-105 Study Group. University of Michigan, Ann Arbor, USA.

Arthritis Rheum. 2005 Apr;52(4):1264-73.

Free radicals and antioxidants in primary fibromyalgia: an oxidative stress disorder?

Bagis S, Tamer L, Sahin G, Bilgin R, Guler H, Ercan B, Erdogan C.; Physical Medicine and Rehabilitation Department, Mersin University Medical School, Mersin, Turkey.

Rheumatol Int. 2005 Apr;25(3):188-90.

LYME DISEASE AWARENESS WEEK

May 4-10, 2005

The California legislature has passed, and Governor Schwarzenegger has signed into law, a resolution declaring May 4-10 Lyme Disease Awareness Week (SCR 23). The measure includes language describing the pervasiveness of the illness, the difficulties of the treatment, and the lack of a cure.

Most notably, the measure states that
“[t]here are fewer than 40 ‘Lyme literate’ physicians in clinical practice in California, resulting in frequent misdiagnosis and under-treatment of patients. This marginalization has led to broken families, financial hardship, job losses, increased numbers of people on disability or welfare, and even death. We have a hidden public health epidemic in need of being addressed promptly.”

Well, duh! (Sorry, I couldn't resist.)

For those who are interested, the full text of the resolution can be found on the Internet at:

http://www.leginfo.ca.gov/pub/bill/sen/sb_0001-0050/scr_23_bill_20050422_chaptered.html.

FROM THE LIBRARY SHELVES

Betsy Waters

One of the great benefits of being a member of *The Carousel Network* is having access to a wonderful variety of information about your illness. The library is an important part of our organization, and has been growing every month. We now have current books about fibromyalgia, CFIDS, Lyme, and MCS, as well as videotapes and copies of handouts from our previous meetings. The library is open for business immediately after the meetings, from 4 – 4:30 p.m. You can check out library materials one month, and return them the next. Please stop by the library table soon and have a look!

CLASSIFIED ADS

The Carousel Network (TCN) is seeking assistance with our monthly meetings in the following areas:

1. **RECEPTIONIST**: Someone to sit at the front desk and help attendees sign in, answer questions, or direct attendees to someone who can answer questions.
2. **SET UP ASSISTANT**: Someone to assist with rearranging tables, if necessary, prior to the meeting, and setting out our library materials on a table top. The Receptionist and Set Up Assistant can be the same person.
3. **VIDEOGRAPHER**: Someone to videotape the speaker at the meetings. We have an older model VHS video camera that can be used. Its operation is fairly simple, and can be learned in a few minutes.

We would need the receptionist from 1:30 – 4 p.m., the set up assistant from 1:30 – 2 p.m. (and 4:30 – 4:45 p.m., if possible), and the videographer from 1:45 – 4:15 p.m. If you would like to volunteer, or know of a teenager or senior (or anyone in between!) who would be willing to help us out, please contact TCN at (707) 324-8881.

ACCUPRESSURE FOR HEADACHE RELIEF

Use your thumb and index finger to press against the bridge of your nose at the corners of your eyes. Or, rub the center of the fleshy webbing between your index and thumb.



One of the benefits of membership in The Carousel Network is receiving the newsletter by mail a week or two before the first meeting listed on the cover. To join The Carousel Network, you can print out our brochure at

<http://www.cndsinfo.net/pdf-files/tcnbrochure.pdf>

and send the completed form with your check for \$20 to:

The Carousel Network
122 Calistoga Rd, #216
Santa Rosa CA 95409-3702



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