

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,

At last month's meeting, Sarah Martel spoke on nutrition, providing us with seven guidelines for healthy eating. (If you missed the meeting, and would like a copy of her handouts, please contact TCN.) Her talk was general in nature, giving important information on nutrition for everyone, healthy and sick alike. To provide more detailed information on nutrition, specific to people with chronic neuroimmune diseases, we have turned to the experts. This month's edition of the newsletter contains Part 1 of a lengthy article outlining the nutritional and supplementation advice of some of the leading physicians treating our illnesses. (Part 2 will follow in the next issue.) You will notice that, while there is some general agreement between the experts on nutrition and diet, there are differences in approaches to supplementation. As you read through their advice, please remember that you should always consult your own doctor before changing your treatment regimen.

And, with a name like Pat O'Hara, I couldn't let this month go by without wishing everyone a Happy St. Patrick's Day! You will notice a few Irish blessings sprinkling the text of the newsletter, and here's one more:

May you have warm words on a cold evening,
A full moon on a dark night,
And the road downhill all the way to your door.

Pat O'Hara

TCN MEMBERS URGED TO PARTICIPATE IN MAY 1 *MILLION* LETTER CAMPAIGN

Pat O'Hara

For the past decade or so, May 12 has been designated Awareness Day for chronic neuroimmune diseases (CND) such as CFIDS, fibromyalgia, and multiple chemical sensitivities. This year, with our new awareness of Lyme disease as a CND which affects many of us, we are adding it to the list as well. Every year on May 12, individuals and support groups around the world have engaged in activities to spread awareness of our 'invisible' illnesses among the medical community, our lawmakers, and the general public. For years, the CFIDS Association of America has sponsored a Lobby Day, where people with CNDs travel to Washington, D.C. to visit with lawmakers to inform them about our illness, and how we are being underserved by medical and disability providers, to stimulate discussion on how new laws and regulations could help our situation.

With our illnesses, traveling to Washington, D.C. (or anywhere else), staying in a hotel, and spending a full day visiting and talking to legislators can be debilitating and painful, and, for most, not well-advised. This year, Pattie Caprio, a reader of *Dominie's Newsletter* (www.fms-help.com), came up with the idea of getting as many people as possible to send letters on the same day to a select group, including the White House and several national news outlets. The impact of these potentially millions of letters hitting their desks on the same day would pack a significant wallop. I know that I have had days when I have felt powerless to help myself or anyone else with our illnesses to overcome the apathy and ignorance of people who do not have CNDs, or are not familiar with the daily trials and tribulations of someone who does. Now here is my chance to do something, and yours too.

The plan is for everyone to send five letters: to the White House, ABC News (20/20), Fox News, CBS News/60 Minutes (Mike Wallace has experienced chronic illness), and Montel Williams (who has Multiple Sclerosis). The letters do not have to be long—one page is enough to get the point across. The letter should contain the following:

Your name.

Your location (city, state and/or county).

Occupation or achievements prior to becoming ill.

Date of onset of your illness, and what you think caused it.

Symptoms you experience due to your illness.

How this illness has affected your career, finances, relationships, family, etc. (be sure to mention any losses you may have experienced).

What you are asking for: e.g., recognition of this illness, for doctors and lawyers to take CNDs seriously for disability cases, for understanding from family and friends, for money to be spent on research for a cure, for media coverage, or whatever else comes to mind.

This sounds like a lot to say in a one-page letter. Actually, most of us could write a book, given the time and energy required to do so! However, this can be

done in a single page. An example of such a letter is given on the next page. This is the letter I intend to send—please feel free to copy any and all portions of it that are useful to you, or compose one of your own.

With each letter you write, each stamp you place on the envelope, and each envelope you deposit in the mailbox, you will gain a sense of power over your situation. Five letters—we can do that, can't we? (And if you think you can do more, please contact TCN for ideas on where else to send them.) So please start your preparation now, and mark your calendars to deposit your letters in the mailbox on May 1.

Pat published in the newsletter her personal letter to ABC News:

May 1, 2005

Story Editor
20/20, ABC NEWS
147 Columbus Ave., 10th Floor
New York, NY 10023

RE: Request for serious media coverage for CFIDS, Fibromyalgia, Multiple Chemical Sensitivities and Lyme Disease (Chronic Neuroimmune Diseases)

My name is Pat O'Hara, and I live in Santa Rosa, California. I have CFIDS (Chronic Fatigue/Immune Dysfunction Syndrome). Eight years ago, I was an executive with a Silicon Valley company. I was on the way up in what had been a 15-year career streak. I had earned both B.S. and M.S. degrees in Chemical Engineering, and was considered an expert in my field. Then I got sick.

The symptoms of my illness struck suddenly in the summer of 1997. I was struck with what appeared to be the flu—fatigue, nausea, body aches, dizziness and fainting, fever, sore throat, and swollen glands. I began to suspect something was seriously wrong when the 'flu' did not go away after two weeks. After a year of doctors visits and lab tests, I was finally diagnosed with CFIDS, a debilitating illness of unknown origin—and a poor prognosis. I now suffer from immune system dysfunction (constant reactivation of viral and bacterial infections, multiple allergies and autoimmune illnesses), neurological and cognitive dysfunction (autonomic nervous system dysregulation, attention deficit, difficulty speaking and short term memory deficit). Other disorders I have which are exacerbated by CFIDS include degenerative disk disease (requiring major surgery in 2002), bone loss, and joint problems.

Due to this illness, I can no longer work. My finances have suffered due to reduction in income—and my plans for a comfortable retirement in my old age have been completely derailed. Relationships with my family and friends have suffered because I no longer have the strength and stamina to engage in most social activities.

I am writing to ask you for serious media coverage of these diseases, and their effects on the lives of those who contract them. Many are unaware of the devastation that these diseases cause to all facets of the lives of those affected. Medical professionals are often not aware of these diseases, or, if aware, they may be relying on outdated and incorrect information about how they manifest, their treatment, and their long-term prognoses. Disability insurers frequently rely on this same outdated information when evaluating and managing disability claims. While statistics show that the financial impact to society from these diseases is huge (the CDC estimates lost

productivity to be \$9 billion in the U.S. alone!), very little is being spent on research into their causes and effective treatments. And last, but by no means least, the general public, which sometimes sadly includes our very own friends and family, are often uninformed, or misinformed, about our illnesses, leading to major strains, and sometimes loss of relationships.

Thank you for your help.

Sincerely,
Pat O'Hara

Other addresses to send letters to:

THE FIRST LADY, WHITE HOUSE
1600 Pennsylvania Ave., NW
Washington, DC 20500

FOX NEWS
5151 Wisconsin Ave., NW
Washington, DC 20016

Story Editor
60 MINUTES, CBS NEWS
524 W 57th Street
New York, NY 10019

Senior Supervising Producer
MONTEL WILLIAMS
433 West 53rd St.
New York, NY 10019

**DIET & NUTRITIONAL SUPPLEMENT RECOMMENDATIONS
FROM LEADING FIBROMYALGIA AND CHRONIC FATIGUE
SYNDROME PHYSICIANS—PART 1**

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

We've all heard the expression "you are what you eat." While there is no question that diet and nutrition have a significant impact on overall good health, the extent to which this is true in people suffering from disease is a subject of much debate and has been the topic of many research studies. When you're struggling with a chronic illness such as fibromyalgia (FM) or Chronic Fatigue Syndrome (CFS), this expression takes on a whole new meaning and weight.

While there is no diet or nutritional regimen that has been proven to eliminate all of the symptoms of FM or CFS, there are nutritional strategies that involve changing what you eat – and the way you eat, that help a great many patients feel better, resolve some symptoms, and function at a much higher level.

The dietary and nutritional supplementation advice that follows is provided by respected CFS and FM physicians and experts. While dietary and nutritional changes must be experimented with and tailored to each individual patient according to particular symptoms and deficiencies, the recommendations that follow broadly address the spectrum of nutritional issues that CFS and FM experts regularly encounter with patients, and describe the best solutions they have found.

CHARLES W. LAPP, M.D.

Charles Lapp, M.D., is nationally recognized and sought after as a medical consultant regarding CFS and FM. He is Co-Chairman of the Clinical Affairs Committee for the American Association for CFS, medical advisor to the CFIDS Association of

America, and a board member of the American FM Syndrome Association. Dr. Lapp is currently Director of the Hunter-Hopkins Center, P.A., Medical Consultations, in Charlotte, North Carolina, where he is a practicing physician, and is also Assistant Consulting Professor at Duke University Medical Center in Durham, North Carolina. For more information about Dr. Lapp, visit his Web site at <http://www.drlapp.net/main.htm>.

Diet (foods to eliminate, excitotoxins, etc.): There is very little study of this aspect, but empirically my patients do best on a low fat diet with lots of fresh fruits and vegetables, complex carbs (like rice and potato), and light meats (chicken, turkey, scaly fishes).

We have also found that PWCs [persons with CFIDS/FM] do not tolerate several items: sugar, caffeine, alcohol, tobacco, and excitotoxins like MSG and aspartame (Nutrasweet, Equal). Saccharin (Sweet N' Low) is satisfactory, however. These are remembered by the mnemonic SCATE. Many patients with loose stools may find that reducing dairy and gluten (wheat, barley, oats and rye) intake may help.

Supplementation (how to address any nutritional deficiencies): The literature confirms several deficiencies in CFS and FM, including intracellular magnesium and vitamin B-12, whole body potassium, intracellular ATP, glutathione, taurine, serine, and the short-chain fatty acids such as valine, leucine, and isoleucine. While patients may not feel any better by supplementing these, health can at least be optimized. I frequently recommend supplementation with a multivitamin (like Super Multiple II or Cellular Support), magnesium, potassium, NADH (for ATP), glutathione, and an amino acid capsule.

DEREK ENLANDER, M.D.

Derek Enlander, M.D., is originally from Belfast, Ireland, and is Physician-in-Waiting to the British Royal Family and to several members of the British government during their visits to New York. He is presently in private practice in New York where he sees CFS and FM patients, is on the faculty of Mt. Sinai Medical Center in New York City and serves as President of the Israel Medical Research Foundation. Dr. Enlander has also written and published "The CFS Handbook" which is available through his Web site, <http://enlander-com.mycoolinternet.net/>.

Diet (foods to eliminate, excitotoxins, etc.): Many patients do indeed appear to help themselves by eliminating certain foods. Patients seem to come to these foods and substances by either allergy testing or sample diet reactions. There are many books that can be used as a self-help method to follow. I like for patients to maintain a healthy balanced diet low in animal fat and high in fiber with abundant fresh fruits and vegetables. The treatment that I use to help in this area is a product called Immunoprop. I believe it helps patients in better nutrition for the body, as well as addressing other symptoms.

Supplementation (how to address any deficiencies): The formula injection that I use in treatment provides many amino acids along with minerals and vitamins. With testing results, I may also include additional substances such as potassium, calcium, etc. I find that pills often are not absorbed well, so I prefer to use the injection for better absorption. I am not opposed to discussing other substances that might be of particular help.

However, I want patients to recognize that supplements and herbal medicines have [as] many potential side effects and toxic reactions as standard drug therapy. In fact, the dangers increase due to the lack of standards, doses and quality for ingredients. Vitamin

E has been recommended in low doses to enhance the fatty acids in the cell membrane, and promote cell function.

DANIEL J. CLAUW, M.D.

Daniel J. Clauw, M.D., is Professor of Medicine, Division of Rheumatology, Director, Chronic Pain and Fatigue Research Center, and Interim Director of the Center for the Advancement of Clinical Research at The University of Michigan. Dr. Clauw has been involved in the clinical care of, and research into, overlapping conditions such as FM, CFS, Gulf War Illnesses, and multiple chemical sensitivity, and is widely recognized as a leading authority on these illnesses.

Diet: I don't think there is any diet than can be recommended except a sensible, healthy diet.

Supplementation (how to address any deficiencies): There are a few supplements that may be helpful for FM such as magnesium supplements, or SAM-e, but patients should understand that these are drugs when taken in this way. I am always somewhat amused when a patient comes in to me taking eight different nutritional supplements, and says that he/she doesn't want to take any drugs. A drug is anything that is ingested to change the body's physiology – nutritional supplements are drugs.

MARK J. PELLEGRINO, M.D.

Mark J. Pellegrino, M.D., is Board Certified in Physical Medicine and Rehabilitation and Electrodiagnostic Medicine, and is one of the nation's leading experts on FM. Dr. Pellegrino is the author of numerous books and articles on FM, and despite having FM himself, he maintains an active medical practice in North Canton, Ohio where he has cared for thousands of FM patients.

I often recommend a diet that is higher in protein and lower in carbohydrates to help FM. A variety of nutritional supplements can also be used to help the symptoms of FM. Magnesium with malic acid, 5-HTP, colostrum and others can be beneficial. Many people who are too sensitive to prescribed medicines may better tolerate nutritional supplements.

The research supports that those with FM have low or below normal levels of magnesium, thyroid, growth hormone, B-12 levels and serotonin, among others. If low or below normal deficiencies are identified, I recommend specific supplementation. For [CFS], I often recommend supplements that include magnesium and malic acid, colostrum, and NADH, among others. I also recommend specific dietary strategies for [CFS], namely a diet higher in protein and lower in carbohydrates (as I recommend for FM).

GARTH NICOLSON, Ph.D.

Garth Nicolson, Ph.D., is President, Chief Scientific Officer and a Research Professor at the Institute for Molecular Medicine in Huntington Beach, California. He is engaged in research on the role of chronic infections in a variety of illness, including CFS, FM, Rheumatoid Arthritis, Gulf War Syndrome, and various autoimmune diseases. For more information about Dr. Nicolson, visit his Web site, <http://www.immed.org>.

At the core of Dr. Nicolson's approach to CFS and FM are his findings on chronic infections in these disorders. Dr. Nicolson has found through his research studies that

the majority of CFS and FM patients have chronic viral and bacterial infections. Infective agents receiving particular attention from Nicolson are mycoplasmas, which he describes as "bacterial microorganisms lacking cell walls that are capable of invading several types of organs, tissues and cells." In his investigations, Dr. Nicolson has found that two-thirds of his patients with CFS or FM test positive for mycoplasmal infections in their blood.

Dr. Nicolson does not necessarily believe mycoplasmas are the initial cause of CFS or FM. Rather, he feels that possibly exposures to chemical toxins, acute viral illnesses or trauma of some sort can open the door for these infections. Once in the door, Dr. Nicolson explains that mycoplasmas become "stealth" invaders because "they can avoid immune surveillance and penetrate and hide in various tissues and organs." The results of this invasion are immune suppression, allowing further viral attack and promoting chronic inflammation with associated symptoms of chronic fatigue, muscle weakness and pain.

Diet: Dr. Nicolson recommends a controlled diet, two-thirds of which is composed of vegetables, one-sixth starch and one-sixth protein. The vegetables should be green, orange, and yellow and the majority of vegetables eaten should be cooked. The starch should be whole grain and include complex carbohydrates. The protein can include chicken, fish, beans and lean, well-cooked meats.

While some fruit is okay, a large concern of Dr. Nicolson is keeping dietary sugars low. Thus, fruit lower in sugar content is better, and fruit juices are discouraged. On the other hand, vegetable juices, herbal teas and plenty of water are beneficial to keep the body cleansed. Dr. Nicolson's concern about sugar is based upon sugar's promotion of mycoplasmas and other harmful microorganisms. For this reason, as much as possible, food and drink containing sugars should be eliminated from the diet. Refined, fatty, and yeast containing foods are also good to avoid. Likewise tobacco, alcohol, and caffeine would not be included in a diet most helpful for CFS.

Supplements: Dr. Nicolson encourages the use of supplements to strengthen patients' immune systems and to improve overall health. B complex vitamins in easily assimilated forms, such as sublingual, are important. Vitamins C, E, CoQ10, amino acids, and minerals such as zinc, magnesium and calcium should be taken. Dr. Nicolson also recommends fish, flaxseed oils and mixtures of friendly bacteria including lactobacillus acidophilus. Especially beneficial for a strong immune system are bioactive whey products, lemon/olive drinks, olive leaf extract, fresh garlic, oregano oil and mushroom extracts.

DALE GUYER, M.D.

Dale Guyer, M.D., is the Medical Director of the Advanced Medical Center in Indianapolis, Indiana. The Advanced Medical Center is a multidisciplinary treatment facility which emphasizes a holistic basis. The center utilizes the collective expertise of an oriental medicine doctor, a naturopathic physician, and is currently in the process of creating a unique spa like environment and personalized training exercise facility to effectively help individual patients navigate an optimal health experience by incorporating the best avenues of mind, body, and spirit. Dr. Guyer's Web site is <http://www.daleguyermd.com>.

I think the digestive – and, for that matter, the detoxification system, are often the crux or obstacles that get in the way of significant healing, and of course when someone does not digest and absorb effectively, their cellular nutrient profiles are going to be

inherently deficient. Therefore, first I like to approach the symptoms with natural therapy such as enteric-coated peppermint oil for bowel spasms, which can be used on an as-needed basis.

Secondly, most people need to supplement with digestive enzymes and tailor to the dosing amount that improves overall function and reduces irritable bowel complaints. In addition, some people will need to take small amounts of hydrochloric acid as their own stomach hydrochloric acid output is diminished. Also, most patients have alterations of the intestinal ecology and will need supplementation of probiotic bacteria, and sometimes, initially at least, many patients will need a broad array of different types of probiotics, and so often times for the first several weeks I will have patients take 3 or 4 different brands which provide different spectrums of biologically active probiotic bacteria.

Also, there will often tend to be yeast overgrowth, especially in those who have ever been on any kind of antibiotic therapy. It is often beneficial to do a CDSA (comprehensive digestive stool analysis – Great Smokies Diagnostic Laboratory performs such analyses).

If yeast organisms are noted on the CDSA, a sensitivity analysis can be completed that will show what antifungal medicine or natural compound the organisms are sensitive to. Some people will often require multiple antifungal drugs. One of my favorite regimens, at least from the natural options, is oregano oil. This always seems to offer improvement in most patients. Where I find that approach incomplete, I will usually use combinations of Diflucan and Nystatin, and if that is ineffective, I add Amphotericin. This needs to be prepared by a compounding pharmacy and often several weeks of therapy will be required.

It is also important when using systemic antifungal agents such as Diflucan to be sure to periodically check on liver function, although I must say in the hundreds of patients I have treated, I have never seen any problems or complications with these specific medical regimens. However, in our patients, we also support liver detoxification with products including milk thistle extract and phosphatidylcholine.

MICHAEL E. ROSENBAUM, M.D.

Michael E. Rosenbaum, M.D., is a pioneer in Nutritional Medicine with 25 years experience in alternative healthcare, specializing in the treatment of CFS, FM, Myofascial Pain, endocrine and metabolic disorders, and allergies. He is currently in private medical practice in Corte Madera, California.

A menu of medications, nutrients and herbs help the treatment of sleep, low energy, pain, and depression for CFS and FM patients. The following nutrients and alternative approaches have worked best in my practice:

Energy: B Complex vitamins, especially vitamins B-1 and B-12; NADH – a stabilized form of vitamin B-3, and Coenzyme Q10. These vitamins all participate in the formation of ATP energy packets. For muscle energy, creatine, carnitine and branched chain amino acids are often very useful.

Cognitive function: I strive to raise brain acetylcholine (a neurotransmitter) with tyrosine, N-acetyl carnitine and DMAE which I find helpful; stabilizing brain cell membrane functions with phosphatidylserine is also beneficial.

Anxiety: Magnesium, and relaxant herbs are helpful.

Depression: I recommend amino acid neurotransmitter precursors phenylalanine, tyrosine and tryptophan or 5-HTP. The prominent methylating agent SAM-e is an especially potent mood enhancer which I believe is also useful in helping to reverse chronic nerve damage.

Sleep: It is important to preserve stage 4 deep or 'slow wave sleep.'

Stage 4 sleep is interrupted by benzodiazepines like lorazepam that are frequently used by CFS patients. Tricyclic antidepressants like Elavil and Sinequan are also excellent sleep inducers and enhance stage 4 sleep, but can impair dreaming during REM sleep and cause weight gain. Sonata does not disrupt any of the sleep stages and is particularly useful with middle of the night awakening due to its rapid disappearance from the blood stream.

I have found that a combination of calcium (600 to 800 mg) and magnesium (300 to 500 mg) taken before bedtime has a relaxant effect that is very useful for sound sleep and to prevent restless legs. Melatonin and serotonin inducers like tryptophan and 5-HTP are also very useful. However, too much tryptophan can cause bizarre and unpleasant dreams. GABA, which occupies GABA receptors, helps allay anxiety and induces sleep. Typical dosages are 500 to 1500 mg.

Muscle pain: MSM at high doses of 8 to 12 grams a day is useful. DLPA (phenylalanine, an essential amino acid formed from protein) at doses of one to three grams a day increases endorphins.

Joint aches: I recommend all antioxidants which are anti-inflammatory. Fish oil supplements – especially those with a high EPA content (an excellent source of Omega-3 fatty acids), are also anti-inflammatory and therefore can be helpful for aching joints.

[Ed: Stay tuned for Part 2 of this article, coming in the May/June issue of the newsletter.]

WHAT YOUR DOCTOR DOESN'T KNOW CAN HURT YOU

by Judith Reichman, January 11, 2005, msnbc.msn.com

Think medical-history forms are a bore? Think again, says Dr. Judith Reichman — not completing them could put your health at risk.

Q: *I hate those long medical-history forms you fill out at the doctor's office. They seem to ask for information that seems irrelevant to my situation. Are they really necessary?*

A: Yes — they are essential. You should fill out those forms thoroughly and update them every time you see the doctor.

Although most doctors do their best to keep up with your medical history, you cannot assume that this is the case (or that he or she even reviews that all-important first page of your chart). And with doctors busier than ever, you cannot always rely on them to ask all the questions that may be relevant to your health.

Worse, changes in insurance plans sometimes mean changes in doctors, and the "getting to know you" phase must be repeated each time.

In either case, if the doctor does not have a complete and updated medical-history form, you are putting your health at risk.

I'm glad when a patient comes to her appointment with a list of medical-history information and of questions. All too often, important issues arise from a "by the way" comment as the patient is about to exit the exam room. Then there are those who call later, saying, "I forgot to tell you...." These are not the best ways to get timely diagnosis and therapy.

The following information should be included in your medical history:

GYNECOLOGICAL HISTORY

Since this is a women's health column, I'll begin with gynecological topics.

When did your period start?

The earlier it starts and the later it stops (in other words, the longer you have had periods), the greater is your risk for breast and ovarian cancer.

Are your cycles regular?

Missed periods could indicate too little estrogen — a cause of osteoporosis. Irregular cycles could signal polycystic ovary syndrome (PCOS), a condition often accompanied by acne and weight gain. PCOS may increase the risk for infertility, uterine cancer, hypertension and heart disease.

How long, heavy or painful are your cycles?

Severe pain or heavy bleeding may indicate endometriosis, uterine fibroids or ovarian cysts.

If you have premenstrual symptoms, how severe and long-lasting are they?

There is no reason to suffer PMS in silence — it can be treated. In addition, a determination needs to be made to separate its effects from underlying clinical depression.

How many times have you been pregnant, and how many deliveries, C-sections, miscarriages or terminations have you had?

Multiple deliveries could increase your risk of pelvic support problems. A history of miscarriages could indicate an autoimmune disorder. Also, having a large baby (more than 9 pounds) may mean you are at risk for diabetes.

Do you have a history of infertility?

An inability to conceive — as well as the use of infertility therapies — could increase your risk for ovarian cancer.

What have you used for contraception?

The use of birth-control pills decreases your risk for ovarian and uterine cancer.

Do you feel that your sexual desire or pleasure are diminished or absent?

This can be due to hormonal, physical or emotional problems. Your doctor can help you diagnose the cause and find appropriate treatment.

Have you had a sexually transmitted disease?

If you have had genital warts, chlamydia, pelvic inflammatory disease, trichomonas, herpes or a previous abnormal pap smear, you should maintain a rigorous schedule of pap smears.

Are you menopausal and do you have distressing symptoms?

Hot flashes, mood swings, vaginal dryness and sleep disturbances are treatable. Very early menopause — before age 40 — puts you at risk for osteoporosis and coronary disease.

GENERAL MEDICAL HISTORY

The above questions relate only to your gynecological history. There is, of course, other background information that your doctor should know. This includes:

Past illnesses

Rheumatic fever in childhood, for example, can lead to mitral valve prolapse, meaning you must take antibiotics before dental work to guard against a heart infection called bacterial endocarditis.

Blood transfusions

If you have received blood, your doctor may want to test for Hepatitis C. Transfusions in the 1980s could have put you at risk for HIV infection.

Family history

This is revealing of your genetic risk. You share half of your genes with each parent and sibling, and a quarter of your genes with each grandparent. A family history of heart disease, diabetes, stroke, osteoporosis, arthritis, Alzheimer's and many cancers can increase your risk for these diseases and warrant specific testing (and, in some cases, behavior modification).

Medications

Your doctor should know what medications you are taking. This includes any over-the-counter drugs, vitamins, minerals and herbs. (Just because something is labeled "natural" does not mean that it does not have potential harmful effects and/or interactions with other medications.)

Health habits

Smoking, alcohol consumption, diet and exercise — own up to what you are (or aren't) doing.

Sleeping patterns and energy levels

Fatigue may be due to inadequate sleep, stress or an underlying disease.

Drug allergies

Whenever you get a new prescription, remind your doctor about previous drug allergies. Many medications share a similar chemical structure that will renew old allergic reactions.

Recent foreign travel

More and more people are traveling the globe — and are exposed to new viruses, bacteria and parasites. Keep your doctor informed.

Finally, ask your doctor whether you are due for screening tests or immunizations. Depending on age and risk factors, you should be given a schedule for your mammogram, pap smear, blood tests, colon testing and bone-density test.

Dr. Reichman's Bottom Line: What your doctor doesn't know can hurt you. It's important to keep those forms at the doctor's office complete and current.

FROM THE NEWSWIRE

MedWatch - The FDA Safety Information and Adverse Event Reporting Program

Eli Lilly and FDA notified healthcare professionals of reports of medication dispensing or prescribing errors between the atypical antipsychotic ZyPREXA (olanzapine), indicated for the short-term and maintenance treatment of schizophrenia and for the short-term treatment of acute mixed or manic episodes associated with Bipolar I Disorder, and the antihistamine ZYRTEC (cetirizine HCl) marketed by Pfizer, indicated for the treatment of allergic rhinitis or chronic urticaria. These reports include instances where Zyprexa was incorrectly dispensed for Zyrtec and vice versa, leading to unnecessary adverse events or potential relapse in patients suffering from schizophrenia or bipolar disorder. Read the complete MedWatch 2005 safety summary, including links to the Dear Healthcare Professional letter, at <http://www.fda.gov/medwatch/SAFETY/2005/safety05.htm#ZyPREXA>.

Sunlight makes the pain go away

In another sign conventional medicine may indeed be catching up to alternative treatments that are far less toxic and actually helpful, increasing the sunlight in a patient's hospital room lessens the need for painkillers and [alters] the way one perceives pain, according to new research. After their surgeries, 89 hospital patients were randomly assigned rooms that were dim or sunny. According to measurements taken by a light meter, patients in darker rooms received almost half as much sunlight than those staying in sunnier rooms. Not surprisingly, patients in dimmer rooms needed more painkillers – an additional 28 percent per hour – while hospitals spent 21 percent less on average for such drugs for those staying in brighter rooms. Moreover, patients placed in brighter rooms after surgery had significantly lower stress scores and marginally lower pain scores when they left the hospital than those staying in darker rooms. Studies like this one remind me just how ignorant conventional medicine can be. Take, for example, the treatment of tuberculosis (TB). In the late 1800s and early 1900s, long before the development of antibiotics, TB was successfully treated by exposing patients to simple sunlight in a solarium. And, with the end of winter about a month away, you'll soon be able to get all the sunshine you'll need to optimize your health. The trick, however, is to be careful to never get burnt. The safe, healthy way is to avoid using toxic sunscreens, as they will block absorbing beneficial UV rays. Sunlight can also do a world of good for other conditions too:

- Lowers high blood pressure
- Prevents cancer
- Improves your ability to sleep

[ABC News, February 16, 2005; *Psychosomatic Medicine*, January/February 2005; Dr. Joseph Mercola, <http://www.mercola.com>]

How to find government benefits that you may be entitled to

There are a couple of online services that can help you discover if there are public

programs and benefits that you may qualify for. These services help to find programs that may pay for some of the costs of prescription drugs, health care, utilities, and other essential items or services. Benefits CheckUp, offered by the National Council on Aging (<http://www.benefitscheckup.org>) is designed for people 55 and over, although it can help identify some programs based on disability or income. GovBenefits.gov (<http://www.GovBenefits.gov>) is sponsored by a partnership of federal agencies, and is designed for persons of any age and circumstance. At each Web site, you can fill out a free, confidential questionnaire to obtain a list of programs that you may be eligible for.

FROM JERRY'S DESK

For any of you who don't know me, a brief introduction. I broke down in 1992 while working for a chemical company. I found this group, and staggered into a meeting having no idea what was really wrong with me. Thanks to the caring people, I was able to educate myself and my doctors. For the last 12 years, I've been working with people in this group, and on an individual basis. As they say, "If life gives you lemons make lemonade." I'd have to say that these last 12 years have been the most rewarding of my life. If I had to say what I have in the way of illnesses, it would be Fibromyalgia, Chemical Sensitivities, and Auto-immune Thyroiditis.

A few miscellaneous thoughts:

1) I apologize if any of you were adversely affected at the February meeting by Sarah bringing in the aromatherapy samples. She had promised me that she wouldn't.

2) You really all need to be at the March 5th meeting. [*Todd Soares, P.T.: Neuroimmune Illness: The Role of Movement and Exercise*]. One of Todd's staff worked on me a few years back. In 10 visits she got rid of the six terrible tender points on my back, and they haven't come back! With these diseases that we have, pain, stiffness, and muscle wasting due to inactivity tend to perpetuate the problem. If you can break the cycle, your body can have a chance to heal. Here is a chance to get help to learn proper exercises that won't cause flare-ups.

3) For years we have wished that we as a group could do something to celebrate May 12th – National CFIDS/FM Awareness Day. This year we have a chance to be heard!

4) In prior years, we have had a second meeting each month focused on sharing, asking questions of each other, and getting to know each other better. Do you have an interest in this type of meeting? If so call (707) 324-8881 or drop us an email at carousel@cndsinfo.net. Please leave your name and phone number so that we can talk to you about how this meeting can best meet your needs. Also, does anyone know of a place where it could be held?

- Jerry Sundahl

RESEARCH BRIEFS

www.pubmed.org

How to obtain more information about research papers is provided following the list of citations.

Urinary electrophoretic profiles from chronic fatigue syndrome and chronic fatigue syndrome/fibromyalgia patients: a pilot study for achieving their

normalization.

Casado B, Zanone C, Annovazzi L, Iadarola P, Whalen G, Baraniuk JN.; Department of Biochemistry A. Castellani, University of Pavia, V.le Taramelli 3/B, 27100 Pavia, Italy.

J Chromatogr B Analyt Technol Biomed Life Sci. 2005 Jan 5;814(1):43-51.

ABSTRACT: Aim of our study was to determine if there were distinct, disease-related patterns of urinary analytes in chronic fatigue syndrome (CFS) and chronic fatigue syndrome/fibromyalgia (CFS/FM) compared to normal controls (NC). Urine was collected from these subjects for two consecutive 24 h periods and aliquots were submitted to micellar electrokinetic chromatography (MEKC). To compensate for the differences in peak migration times, these were normalized from the 35 min duration of run to a 100-point scale, and each peak was assigned its normalized time measure. Peak heights were also normalized by dividing the mAU by that of the internal standard (creatinine) and multiplying by 100. MEKC with normalization for peak height and migration time generated comparable results within each of the patient groups. **CFS/FM and CFS had significant differences in peaks compared to NC that may be of significance as biomarkers of illnesses.**

Antidepressants and antiepileptic drugs for chronic non-cancer pain.

Maizels M, McCarberg B.; Department of Family Practice, Kaiser Permanente, Woodland Hills, California 91365, USA.

Am Fam Physician. 2005 Feb 1;71(3):483-90.

The development of newer classes of antidepressants and second-generation antiepileptic drugs has created unprecedented opportunities for the treatment of chronic pain. These drugs modulate pain transmission by interacting with specific neurotransmitters and ion channels. The actions of antidepressants and antiepileptic drugs differ in neuropathic and non-neuropathic pain, and agents within each medication class have varying degrees of efficacy. Tricyclic antidepressants (e.g., amitriptyline, nortriptyline, desipramine) and certain novel antidepressants (i.e., bupropion, venlafaxine, duloxetine) are effective in the treatment of neuropathic pain. The analgesic effect of these drugs is independent of their antidepressant effect and appears strongest in agents with mixed-receptor or predominantly noradrenergic activity, rather than serotonergic activity. First-generation antiepileptic drugs (i.e., carbamazepine, phenytoin) and second-generation antiepileptic drugs (e.g., gabapentin, pregabalin) are effective in the treatment of neuropathic pain. The efficacy of antidepressants and antiepileptic drugs in the treatment of neuropathic pain is comparable; tolerability also is comparable, but safety and side effect profiles differ. Tricyclic antidepressants are the most cost-effective agents, but second-generation antiepileptic drugs are associated with fewer safety concerns in elderly patients. Tricyclic antidepressants have documented (although limited) efficacy in the treatment of fibromyalgia and chronic low back pain. Recent evidence suggests that duloxetine and pregabalin have modest efficacy in patients with fibromyalgia.

Spinal fluid abnormalities in patients with chronic fatigue syndrome.

Natelson BH, Weaver SA, Tseng CL, Ottenweller JE.; Fatigue Research Center (129), VA Medical Center, 385 Tremont Ave., East Orange, NJ 07018.

Clin Diagn Lab Immunol. 2005 Jan;12(1):52-5.

Benefit of Ribose in a Patient With Fibromyalgia

Gebhart B, Jorgenson J.; Department of Pharmacy Services, University Hospitals and Clinics, Salt Lake City, Utah.

Pharmacotherapy 24(11):1646-1648, 2004.

Remote sensing (normalized difference vegetation index) classification of risk versus minimal risk habitats for human exposure to Ixodes pacificus (Acari Ixodidae) nymphs in Mendocino County, California.

Eisen RJ, Eisen L, Lane RS.; Division of Insect Biology, University of California, Berkeley, CA 94720, USA.

J Med Entomol. 2005 Jan;42(1):75-81.

Stress-associated changes in the steady-state expression of latent Epstein-Barr virus: Implications for chronic fatigue syndrome and cancer.

Glaser R, Padgett DA, Litsky ML, Baiocchi RA, Yang EV, Chen M, Yeh PE, Klimas NG, Marshall GD, Whiteside T, Herberman R, Kiecolt-Glaser J, Williams MV.; Department of Molecular Virology, Immunology and Medical Genetics, The Ohio State University Medical Center, 333 W. 10th Avenue, Columbus, OH 43210, United States; Institute for Behavioral Medicine Research, The Ohio State University, 333 W. 10th Avenue, Columbus, OH 43210, United States; Comprehensive Cancer Center, The Ohio State University, 300 W. 10th Avenue, Columbus, OH 43210, United States.

Brain Behav Immun. 2005 Mar;19(2):91-103.

Case-control study of genotypes in multiple chemical sensitivity: CYP2D6, NAT1, NAT2, PON1, PON2 and MTHFR.

McKeown-Eyssen G, Baines C, Cole DE, Riley N, Tyndale RF, Marshall L, Jazmaji V.; Departments of Public Health Sciences, University of Toronto, ON, Canada.

Int J Epidemiol. 2004 Oct;33(5):971-8. Epub 2004 Jul 15.

How to obtain more information: More information about the research papers listed here, including abstracts and, occasionally, full text of the articles, can be obtained for free at www.pubmed.org, or by contacting the TCN Editor at (707) 324-8881 or newsletter@cndsinfo.net.

If you would like a copy of the full text of a paper, and it is not available for free online, you can go to the publisher and pay full price—or order the article through your regional public health library (PHL). Article reprints that may cost \$30+ from the publisher will cost \$14 through Loansome Doc (which connects you to your regional PHL). If you join the PHL, it will cost even less.

For a \$15 annual fee, you can join the Redwood Health Library, and get access to the password protected areas at their site, and pay only \$8 for copies of articles they obtain from other libraries. If you do not have access to the internet, you may also obtain articles by visiting the library, or contacting the librarian at the phone number below.

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www.phcd.org/rdwplib.html

Loansome Doc: www.phcd.org/ld.html

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FROM THE LIBRARY SHELVES

Betsy Waters, TCN Librarian

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!

HEALTH ADVISORY—STOP MAKING YOUR BED!

Yes—you read that right! Building scientists at Kingston University in London have been investigating whether clutter could actually be the key to healthier living. Dr Stephen Pretlove, from Kingston University's School of Architecture, is one of a group of specialists advising us to leave our beds unmade to banish house dust mites which cause asthma and other allergies. The scientists have discovered the mites cannot survive in the warm, dry conditions found in an unmade bed.

At last! A health advisory that's compatible with the strength, stamina and physical mobility limitations of people with CFIDS/FM/MCS/Lyme!

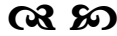
CLASSIFIED ADS

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.

*May your blessings outnumber
The shamrocks that grow;
And may trouble avoid you
Wherever you go.*



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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