

# HEALTHwatch™

## SPECIAL EDITION: ANNUAL CFS & FM TREATMENT GUIDE



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### CFS Specialist Jacob Teitelbaum, M.D., Makes His Treatment Program Widely Available

By Patti Schmidt

*Patti Schmidt is an award-winning writer and PWC (Person with CFIDS), a former CFIDS support group leader, co-founder of the Greater Philadelphia CFIDS Alliance, and is an officer of the Board of Directors of the CFIDS Association of America. Ms. Schmidt has written about a wide variety of topics relating to coping with the disease and seeking out effective treatment.*



Jacob Teitelbaum, M.D.

Most people with CFS or FM recognize Dr. Jacob Teitelbaum's name: he's been published in all the relevant journals; many have read his best selling book, *From Fatigued to Fantastic* and he maintains a well-known website. He also treats many patients and as a result, generates much word-of-mouth promotion within the community. In addition, he has belonged to a few patients' groups online - because, unlike most other physicians who treat CFS and FM patients, Dr. Teitelbaum has experienced these diseases first-hand.

After growing up in Cleveland, Ohio and finishing college in two-and-a-half years, he was studying to be an internist with special interests in endocrinology, nutrition and muscle disorders at Ohio State University Medical School. In 1975, he came down with "the flu" and for the next year was unable to return to school. He suffered from symptoms for years afterward; to this day, he still gets a few symptoms if he "does stuff that's not healthy...my body will call me on it," he laughs. But he considers those last few symptoms a kind of early warning system his body wisely and generously provides him so he knows when he's heading down a path that's not good for him. "I wouldn't get rid of those last few things if I could," he says. "They're my body's circuit-breaker. They protect me."

**Life-changing experience**

The illness he experienced and which interfered with his attending medical school changed his life and set him on his current path - to make a difference in the lives of CFS and FM patients. When he was ill, he didn't know what it was that he had, but he knew it was real, it was "something," and it was "devastating - it knocked me out of medical school for the year."

Dr. Teitelbaum did his residency training at Washington Hospital Center in Washington, D.C., from 1977-1980. His next stop was an HMO in Annapolis, Maryland, which was going out of business when he joined it, unbeknownst to him. Six months later, the practice was finished. That event, which might be considered bad luck by some, turned out to be a blessing, says Teitelbaum now.

"I love Annapolis, and that job got me here," he says now. "And my  
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### Dale Guyer, M.D., on Treating Chronic Fatigue Syndrome & Fibromyalgia: "Covering the Bases & Peeling Back the Layers of the Onion"



*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.*

**ImmuneSupport.com:** Dr. Guyer, let's discuss some of the factors that in your experience are primary contributors to ongoing Chronic Fatigue Syndrome and fibromyalgia, and what treatments you are finding to be most effective. A common primary issue is the challenge of getting regular, quality sleep. What therapies have you found most helpful for CFS and FM?

**Dr. Guyer:** To date, some of the better treatments I have found for this problem always involve an incorporation of exercise and proper diet, or at least exercise as tolerated, but often times many patients do not respond to the usual array of sleep medicines and other concoctions or need additional therapy to more broadly support their sleep quality. In that context, my favorite formulation is a compounded preparation that I have done for me at a pharmacy. I combine Tryptophan 500 mg, 5-HTP 125 mg, and Melatonin 2.5 mg per capsule. The patient usually takes 2-4 capsules at night 30 minutes before bed. In my experience, this has been an enormous help to stabilize sleep quality. It also helps in decreasing pain by augmentation of the Serotonin pathway.

The second thing that I have been overwhelmingly impressed with is the new Cuddle Ewe mattress pad, and like most therapeutic options, I tried it on myself prior to recommending it for patients. Even though I do not have CFS, I have noticed my sleep quality and that of my wife and our four month-old has been significantly better since using the Cuddle Ewe mattress pad. Even more importantly, I have seen dramatic improvement in many of my FM patients who have had enormous difficulty attaining quality sleep despite trying some of the more promising sleep aids on the market.

**ImmuneSupport.com:** It sounds like these therapies are helpful adjuncts for stabilizing sleep. In addition, what have you found to be most useful in improving overall energy status in fighting fatigue in these patients?

**Dr. Guyer:** To enhance energy level, some of the best adjunctive therapies I have found to date include intravenous vitamin therapies in which the patient receives, through an intravenous infusion, a mixture of Vitamin C, Trace Minerals, Glutathione, NADH, ATP, AMP, Magnesium, Calcium, B Complex, Vitamin B12, and other additions depending on clinical need. In addition, we will often teach our patients to do their

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## Research News Briefs

### Study Reports: ULTRACET Effective for Treating Fibromyalgia Pain

The National Fibromyalgia Association (NFA) announced on June 12, 2003 that a recent study reports that ULTRACET (tramadol hydrochloride/acetaminophen) has been found to effectively reduce pain in people with fibromyalgia. The study, published in the American Journal of Medicine, was led by researcher Robert M. Bennett, M.D., a pain specialist at the Oregon Health and Science University. In the 91-day, multi-center, outpatient, double-blind, randomized, placebo-controlled study, Dr. Bennett compared ULTRACET (37.5 mg tramadol hydrochloride/325 mg acetaminophen tablets) to placebo in 315 fibromyalgia patients. Patients who used ULTRACET experienced significantly better pain relief, as indicated by statistical analysis, than those who received placebo. Outcome variables included cumulative time to discontinuation (Kaplan-Meier analysis), final pain visual analog scale scores, final pain relief rating scale scores, total tender points, average myalgic scores, SF-36 Health Survey scores and Fibromyalgia Impact Questionnaire scores.

Although ULTRACET has received some exposure in the medical industry, not all physicians know about it. "A lot of patients actually have to educate their doctor," notes Dr. Bennett, "but they might want to do it diplomatically," he adds. In the U.S., ULTRACET is approved for the treatment of short-term (five days or less) management of acute pain. (Source: Announcement from The National Fibromyalgia Association by Lynne Matallana, President. Website: <http://www.fmaware.org>.)

### Lactic Acid Bacteria of Therapeutic Value for CFS?

Research at the CFS-FM Integrative Care Centre in Toronto, Canada showed that patients with CFS have marked alterations in microbial flora, including lowered levels of bifidobacteria and small intestinal bacterial overgrowth (SIBO). The researchers cited other studies that indicated that CFS patients are under increased oxidative stress, have a type 2 helper cell dominated cytokine profile, frequently report allergies, have altered essential fatty acid (EFA) status and may have malabsorption of certain micronutrients. The researchers proposed that lactic acid bacteria (LAB) have the potential to influence the immune system in CFS patients by supporting T helper cell 1 driven cellular immunity and may decrease allergies. In addition, LAB are strong antioxidants, may improve EFA status, can enhance absorption of micronutrients by protecting the intestinal epithelial barrier, and have been used to treat SIBO. For these reasons, the researchers concluded that LAB may have a therapeutic role in the treatment of CFS. (Source: Logan AC, Venket Rao A, Irani D. Med Hypotheses 2003 Jun;60(6):915-23.)

### Collagen and Muscle Pathology in FM Patients

Muscle biopsies were obtained from 27 female fibromyalgia (FM) patients, and from eight age-matched female control subjects. Amino acids were determined by HPLC and electron microscopy was performed. The FM patients had lower hydroxyproline and lower total concentration of the major amino acids of collagen than the controls. No significant difference was seen in the concentration of the major amino acids of myosin or of total protein. Electron microscopy showed no significant differences between FM patients and controls although atrophied muscle fibrils occurred in FM patients only, but frequencies were not significantly different. It was concluded that the fibromyalgia patients studied had a significantly lower amount of intramuscular collagen. This may lower the threshold for muscle micro-injury and thereby result in non-specific signs of muscle pathology. (Source: Rheumatology (Oxford). 2003 Jul 16. Gronemann ST, Ribel-Madsen S, Bartels EM, Danneskiold-Samsøe B, Bliddal H.)

## Ending Sleepless Nights: From "The Fibromyalgia Handbook, 3rd Edition: A 7-Step Program to Halt and Even Reverse Fibromyalgia" by Harris McIlwain, M.D.



Harris McIlwain, M.D., C.M.D. is a board-certified 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 fibromyalgia syndrome. Dr. McIlwain is also an author, and the

revised third edition of his popular book, "The Fibromyalgia Handbook: A 7-Step Program to Halt and Even Reverse Fibromyalgia" is now available.

According to rheumatologist Harris McIlwain, M.D., C.M.D., "Since there is no cure (yet), physicians have tried a number of different treatments to try to control the pain, fatigue and other problems caused by fibromyalgia. The program we describe in *The Fibromyalgia Handbook* is one that we've developed over years. This 7-step program offers a majority of patients improvement, helping to make their symptoms manageable and giving them more control in their daily activities. Because I diagnose and treat fibromyalgia syndrome (FMS) daily, I am passionate about finding ways to help my patients ease their symptoms

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HEALTHwatch is published by:

Pro Health, Inc., 2040 Alameda Padre Serra, Suite 101, Santa Barbara, CA 93103. 1-800-366-6056

Editor: Lee Ann Stiff

Graphic Design: Jon Poole

Disclaimer: HEALTHwatch is published for individuals, health professionals and others interested in CFS and Fibromyalgia. Any nutritional supplements discussed in HEALTHwatch are not intended to diagnose, treat, cure, or prevent a disease, but rather are dietary supplements intended solely for nutritional support.  
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### [McIlwain, M.D., continued from page 2...](#)

and regain their active lives. While most patients rely on medications to ease pain, through years of journal research and professional experience, I have discovered that there is much more to resolving fibromyalgia syndrome than simply taking a drug. In *The Fibromyalgia Handbook*, I give a host of safe lifestyle substitutions, winning exercise and nutritional strategies, natural supplements and herbal therapies, mind/body and hands-on therapy tips, as well as the latest medications, that have helped my patients resolve pain - without putting their active lives on hold. For books that tout a miracle cure or breakthrough for FMS, we now know that to be untrue. Yes, some medications, such as the so-called Super Aspirins, can give relief for many FMS patients and can 'cure' symptoms, but they cannot cure the disease."

Following is an excerpt from *The Fibromyalgia Handbook*, addressing the challenge (and vital importance) of refreshing sleep for FM patients.

#### **End Sleepless Nights**

FM patients complain that no matter how long they sleep, it is never restful. Their sleep may be interrupted by frequent awakening, that is, becoming awake enough that they remember these times the next day. Even more common are awakenings that are not remembered but that definitely break up their deep sleep. Most patients tell of waking up day after day feeling exhausted. They feel more tired in the morning, and many have great difficulty in concentrating during the day, just as in other situations where sleep is disrupted. Because obtaining restful sleep is a crucial problem with this disease, it is helpful to understand the characteristics of normal sleep and how this differs from the sleep experienced by FM patients.

#### **Understanding the Stages of Sleep**

Studies have demonstrated that we have a built-in cycle of sleep-wake times along with many other cyclic variations in bodily functions, such as glandular secretions, body temperature, heart rate, blood pressure, and bronchial function. These intrinsic cycles are controlled by a group of nerve cells called a circadian pacemaker. This pacemaker is closely related to parts of the retina (in the back of the eye) and the hypothalamus in the brain. The circadian cycle is actually 25 hours long. Since the cycle is longer than the 24-hour day, some factor must serve to synchronize the body's pacemaker with the external clock time. These are cues from the environment called zeitgebers (from German, meaning "time givers"). The most important and powerful one is light. The hormone most closely linked to the circadian system is melatonin, which is made by the pineal gland in another part of the brain. Melatonin has been shown to synchronize the sleep-wake cycle to 24 hours in some blind subjects who were otherwise unable to live on a 24-hour day.

In adults, sleep is made up of distinct types or stages with specific characteristics defined by brain waves, eye movements, and muscle tension. The two broad categories of sleep include rapid eye movement (REM) and non-rapid eye movement sleep (NREM). It is during REM sleep that we have almost all our dreams. (Arousals from this stage of sleep are usually associated with recall of vivid imagery.) In NREM sleep, there are four different stages - 1, 2, 3, and 4 - characterized by different combinations of brain waves, eye movements, and reduced but not absent muscle tension. In FM, stages 3 and 4 NREM sleep are the most important. These stages are defined by relatively large, slow brain waves (delta waves), absent eye movements, and reduced muscle tension. Other names for these stages are "slow-wave sleep" or "delta sleep."

#### **Fibromyalgia and Sleep**

About 20 years ago, researchers in Toronto discovered that patients with FM had NREM (non-rapid eye movement) stages of sleep "contaminated" by an intercurrent alpha rhythm (like that

of wakefulness). But whether the sleep disturbance caused the FM symptoms or was secondary to the disease itself could not be determined. This group of investigators went on to show that healthy subjects selectively deprived of delta sleep (deep sleep) by being exposed to noise developed periods of delta sleep mixed with alpha waves. Interestingly, when deprived of delta sleep these people experienced some musculoskeletal discomfort and mood symptoms similar to those of the patients with FM. These data suggested that the stage 4 sleep disturbance caused the appearance of the achiness or pain and mood symptoms.

However, it was felt that the effect of delta sleep disturbance on symptoms might be determined by examining the physical and psychological characteristics of the healthy subjects. Their subjects were younger than the patient population with FM and free from illnesses and psychological problems, but they were not particularly physically fit. Yet they had the symptoms of FM when put through the sleep-deprivation process. Their relatively sedentary lifestyle may have been significant, because most reports have pointed to the positive influence of exercise on delta sleep.

Sleep disturbances can be triggered in patients by physical or emotional trauma or by a metabolic or other medical problem. Poor sleep can lead to fatigue with resultant diminished exercise causing worsened physical fitness and the establishment of a vicious cycle of inactivity and sleep disturbance with physical and mood-related symptoms. These problems could help lead to the development of FM.

#### **Hormones and Sleep**

An interesting study published in the *Journal of Clinical Endocrinology and Metabolism* (April 2001) revealed that men seem to become more sensitive to the stimulating effects of corticotropin-releasing hormone (CRH) as they get older. This hormone plays a key role in how your body responds to stress. If you are aroused, you will have higher levels of CRH.

In the study, researchers evaluated the sleep habits of twelve middle-aged men and twelve young men over four nights. On one night, the men all received CRH ten minutes after they were asleep. Both groups of men produced higher levels of stress hormones in response to the CRH. While younger men produced higher levels of cortisol (the main stress hormone involved in the "fight or flight" response), middle-aged men stayed awake longer. They also had less slow-wave or deep sleep than did the younger men, showing that middle-aged men may have an increased vulnerability to stress hormones. This, in part, may explain why insomnia increases in middle age as a result of these dysfunctional sleep mechanisms caused by arousal-producing stress hormones. There are also studies showing that people who spend less time in slow-wave sleep are more prone to depression.

Because of the effects of estrogen on a woman's sleep pattern, it's more difficult to study women and sleep. For women in perimenopause or just prior to menopause, the declining levels of the hormone estradiol may increase your chance of poor sleep. In an intriguing study at the University of Pennsylvania Medical Center in Philadelphia published in *Obstetrics and Gynecology* (September 2001), researchers followed 436 women age 35 to 49 over a two-year period. About 17 percent of the women reported suffering from poor sleep throughout the entire study period. While researchers blamed anxiety, depression, and caffeine consumption as factors that disturbed the women's sleep, they also identified low estradiol levels and hot flashes in older women aged 45 to 49 as responsible for the sleepless nights, even though all women were experiencing regular menstrual cycles and had not yet entered menopause. The study concluded that the decline in estradiol that occurs with ovarian aging might be associated with poor sleep in women. This sleep deprivation results in daytime fatigue and irritability and can even lead to feelings of depression - all symptoms of fibromyalgia syndrome, too.

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### Accurate Diagnosis is Essential for Proper Therapy

Many of the symptoms that FM patients experience are shared by those with other sleep disorders. For example, some patients with obstructive sleep apnea, intermittent blockages of the upper airway at the back of the tongue, which occurs in 2 percent of women and 4 percent of men who are 30 to 60 years old, also complain of unrefreshing sleep and "hurting all over" upon arising in the morning. They also have a history of snoring and other symptoms, including morning headaches, dry mouth, and an increased tendency to doze off during the day. Some patients with sleep apnea have high blood pressure.

If your doctor suspects that your sleep disorder may have a different cause, he or she may recommend that you have a sleep study. Sleep studies, called polysomnography, include an electroencephalogram (EEG), which measures the electrical activity of the brain, as well as the monitoring of oxygen levels, movements of the chest wall and abdomen, and nasal and oral airflow. A sleep study may show apnea (periods without breathing), manifested by absent airflow at nose and mouth in conjunction with ongoing respiratory muscle efforts shown by movement of chest wall and abdomen. An apnea may cause decreases in blood oxygen levels. Sleep is often interrupted at the end of the apnea by awakening. This breaking up of continuous sleep is a major cause of daytime fatigue and sleepiness. Periodic leg movements during sleep, also known as nocturnal myoclonus, may also be associated with alpha intrusions and are a common cause of sleep interruptions. These sleep disorders require specific therapy.

### The Problem of Insomnia

Because patients with FM have a specific type of insomnia, a disorder of initiating and/or maintaining sleep, it is important to apply certain treatment measures. Not only is attention to sleep hygiene important, but such stimulants as caffeine and nicotine must be avoided near bedtime. Regular daily exercise including stretching and aerobic activity, is a form of treatment that can help to consolidate sleep and to alleviate other symptoms. Biofeedback and relaxation techniques, as discussed in chapter 7 of this book, are useful in overcoming problems of initiating sleep. High levels of arousal associated with racing thoughts, worrying, or rumination may also delay sleep onset. Meditation or guided imagery can be used to help the patient relax while focusing on a neutral or enjoyable target.

### Tips to Encourage Sleep

Establishing better sleep hygiene is vital in managing the symptoms of FM. In our clinic, patients have experienced great success with the following suggestions:

- Sleep only as much as needed to feel refreshed and healthy the following day, not more. Curtailing the time in bed seems to solidify sleep; excessively long times in bed seem related to fragmented and shallow sleep.
- A regular arousal time in the morning strengthens circadian cycling and leads to regular times of sleep onset.
- A steady daily amount of exercise probably deepens sleep; occasional exercise, however, does not necessarily improve sleep the following night.
- Occasional loud noises (e.g., aircraft flyovers) disturb sleep even in people who are not awakened and cannot remember them in the morning. Sound-attenuated bedrooms may help those who must sleep close to noise.
- Although excessively warm rooms disturb sleep, there is no evidence that an excessively cold room solidifies sleep.
- Hunger may disturb sleep; a light carbohydrate snack before bedtime may help you avoid sleep disturbances.
- Caffeine in the evening disturbs sleep, even in those who feel it does not.
- Alcohol may help tense people fall asleep more easily, but ensuing sleep is then fragmented.

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patients said I was 'not allowed' to leave town, so I hung out my shingle and set up a practice of my own." That practice, began in 1981, is now called the Annapolis Research Center for Effective FMS/CFIDS Therapies and has grown to be one of the largest general internal medicine practices in Annapolis. "Back then there wasn't even a name for this illness," he recalls. "But one of the most common complaints in every medical practice is fatigue. I realized that something odd was going on when a lot of people with the same particular mix of symptoms I had were coming in to be treated."

An avid reader of the medical literature, Teitelbaum found many studies that he wasn't told about in medical school and began applying them. "I began to treat patients with nutritional and herbal therapies, hormonal support when clinically indicated (despite 'technically normal' blood tests), anti-infectious treatments (including antifungals), physical therapy measures and sleep support," he remembers. "To my surprise, these previously untreatable patients started to get well. I was amazed to see my practice began to fill with patients who were coming in from all over the country." About the time his practice was burgeoning, the names "Chronic Fatigue Syndrome" and "fibromyalgia" were introduced for these illnesses, and he had a bona fide niche.

### His practice and his protocols

Dr. Teitelbaum treated hundreds of patients over the next few years and refined his diagnostic and treatment protocols (to date he's treated more than 2,500 CFS/FM patients). His definitive study, "Effective Treatment for Fibromyalgia & Chronic Fatigue Syndrome: A randomized double-blind placebo-controlled study," was published in the *Journal of Chronic Fatigue Syndrome* in 2001; a preliminary study was published in 1995 in the *Journal of Musculoskeletal Pain*. That study claimed, "The researchers feel that an effective treatment for FMS and CFIDS is now available." Teitelbaum's overall thinking about these illnesses is backed by something most other physicians don't have - regardless of how sympathetic they might be: they've never felt the "holy hell of it," or "the sting of disbelief." He has, and it shows in everything he says and does. For example, during our interview, when I use the word "yucky" to describe how it feels to be not only tired with CFS, but tired of being tired with CFS, he gets it. I hadn't phrased it in a way that a person who'd never has CFS would understand, but it was exactly what I meant, and he could relate to it.

Since Dr. Teitelbaum is personally familiar with many of the co-illnesses that go with CFS and FM, he's also tried many of the most well-known and well-used remedies. As a result, he knows not to recommend Dalmane or Valium for sleep, because they worsen sleep quality. He knows that it's critical to get 8-9 hours of deep, restorative sleep every night. He knows it's totally unacceptable to leave a person in pain. "Having had the illness lets me know exactly what you're going through - I've been there," he says. His personal and professional knowledge of the illness informs his diagnostic and treatment protocols. "Usually, many problems occur at the same time, and you need to treat them simultaneously," says Teitelbaum. "You have to take a detailed history and then translate what those symptoms mean."

Basically, Teitelbaum's regimen can be (admittedly rather simply) summed up this way: "Fix the sleep, nutrition, hormones and infections and the patient will generally feel better." He's described his treatment protocol this way: "The whole protocol consists of more than 150 different treatments that vary from person to person, but let me give you the heart of the protocol. I view this illness not as the enemy but as a circuit breaker. In a house, you have a fuse box and, if there's a power surge, instead of burning out the wiring, it turns off the circuit breaker. That's what this disease is like. It protects people in the face of severe stresses - whether they're situational stresses, toxic exposures, infections, or a host of different things - by turning off that circuit breaker." He considers the circuit breaker to be the hypothalamus in the brain. "What we found in our studies

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- People who awake feeling angry and frustrated because they cannot sleep should not keep trying, but should turn on the light and do something different. You might have a light snack high in carbohydrates, read a book or watch a television show in another room.
- The chronic use of tobacco disturbs sleep.

Another procedure we use to help patients overcome conditioned insomnia is stimulus-control behavior therapy. The goal is to reassociate the bedroom with sleep rather than with frustration and arousal. To achieve this, patients are told that they are "misusing" their bed if they lie awake and frustrated. Richard Bootzin, the behavior therapist who initiated this approach, recommends the following rules:

- Go to bed only when sleepy.
- Use the bed only for sleeping; do not read, watch television, or eat in bed.
- If unable to stay asleep, get up and move to another room. Stay up until you are really sleepy, then return to bed.
- If sleep does not come easily, get out of bed again. The goal is to associate bed with falling asleep quickly.
- Set the alarm and get up at the same time each morning, regardless of how much you slept during the night. This helps the body acquire a constant sleep-wake rhythm.
- Do not nap during the day.

If the above rules are followed, patients will usually sleep little during the first night. By the second or third night, patients are so tired that they fall asleep on the first or second attempt. Sleep patterns then fluctuate for a few weeks, but gradually the bedroom surroundings again become associated with sleep. However, most patients need a lot of encouragement during this difficult reconditioning period.



Precise diagnosis is essential to establish the existence of fibromyalgia and to distinguish this disease from other sleep disorders. Once the diagnosis is made, a multifaceted approach is then required to ensure restful and healing sleep, and may require some combination of supportive psychotherapy, biofeedback-relaxation techniques, physical fitness training, antidepressants, or some other medicine as discussed in chapter 4 of this book, along with careful medical supervision by a physician. HW

*Editor's Note: The preceding excerpt is from Chapter 8 - Step 5, "End Sleepless Nights" of The Fibromyalgia Handbook, 3rd Edition: A 7-Step Program to Halt and Even Reverse Fibromyalgia, and has been reprinted with permission of the author. To purchase a copy, go to [www.ImmuneSupport.com/shop/books.cfm](http://www.ImmuneSupport.com/shop/books.cfm).*

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is that when that happens, there are four things you need to do to turn the circuit breaker back on. You need to get the person eight to nine hours of solid sleep a night. You need to treat the nutritional deficiencies - and they're widespread. You need to treat the hormonal deficiencies; however, blood tests for hormone status are not reliable when the hypothalamus isn't working. Those tests are based on normal hypothalamic function, so if you rely on those tests, you're going to miss the problem. Instead, you determine deficiencies by symptoms," he said.

For example, if he identifies symptoms of inadequate adrenal function, such as low blood pressure and hypoglycemia, then he recommends an adrenal glandular. "Or there might also be an estrogen deficiency, characterized by decreased vaginal lubrication, diminished libido, symptoms that get worse the week before the period and night sweats," he said. "I treat these accordingly, using natural female estrogen from soy. It's critical to treat nutritional deficiencies," he stresses. Since there are dozens of deficiencies, people used to have to take dozens of tablets per day. Not anymore. "Fortunately, there are now powders that can be mixed with water or juice and people can drink something good-tasting once a day," he said. The fourth thing is treating infections. "When you look for and treat these areas, our research shows that 91 percent of patients improve," he said. "A large percentage become totally healthy. We need to treat those key areas, and you also need to treat what 'clicked off' the circuit breaker in the first place, if it's still going on. The entire protocol can also be done without prescription drugs. We've developed it that way. People can go to my website and tailor a complete, all-natural protocol for their specific case."

About the time his preliminary and definitive studies were published, he wrote and self-published the book, *From Fatigued to Fantastic* (picked up by Penguin-Putnam and has sold more than 250,000 copies). But considering that he was trying to treat patients, keep a five-doctor medical practice up and running, lecture and teach other physicians about CFS/FM, raise a family, write books, and tend to his own health and happiness, it's not surprising that at some point, the 40-some-year-old physician realized he simply could not reach as many sick people as he'd hoped. "There were still all these sick people - several million of them - out there without access to effective therapies," he said. "So I had a choice: I could continue to manage a very successful practice or I could basically focus on getting this information out to people." That decision was a "no-brainer," he says now.

#### [The website](#)

Dr. Teitelbaum decided to treat patients at his clinic only five or six days each month, and lecture, teach and write on the other days - essentially, "get the word out." Then he had to figure out what he could do to make his program available to as many people as he could, as inexpensively as he could. The answer for most people certainly wasn't to go see the internist in his Annapolis-based clinic, because his full-scale work-up costs \$5,800.00 and takes about six hours. (He sees only eight new patients each month.)

His book reached hundreds of thousands, but it wasn't specific enough to offer each patient an individualized treatment program to help with the symptoms he or she suffered. He was teaching other physicians about the illnesses and sharing his protocols with them, but he could only teach so many so fast. What about a website, he thought? That question led him, over the next three years, to spend \$500,000 of his own money having a sophisticated diagnostic program developed that allows a CFS or FM patient to go to his website and get a diagnosis and a treatment program tailored to them individually. If they can't get their doctor to order blood tests they need, they can also get a lab requisition form or download a copy of his treatment program to bring to their own doctors.

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## The Healing Power of Exercise: Advice From an FM Patient-Expert



*Claudia Craig Marek, M.A., is an FM patient, medical assistant (to Paul St. Amand, M.D.), counselor, and author of "A Patient-Expert Walks You Through Everything You Need to Learn and Do: The First Year - Fibromyalgia." Ms. Marek has counseled fibromyalgia patients for more than twelve years, and she is also co-author of "What Your Doctor May Not Tell You About Fibromyalgia."*

**HEALTHwatch (HW):** Briefly, what is your history as a fibromyalgia patient? Was it a long time between onset and diagnosis, and how did you go about seeking out and receiving treatment once you were diagnosed?

**Claudia Marek (CM):** I have had fibromyalgia syndrome (FMS) essentially all my life. I began with bladder symptoms before I started school, then progressed to IBS (Irritable Bowel Syndrome) in grade school, severe pelvic pain and headaches in high school, and more and more pains and fatigue: back, legs, arms, etc. Later I had exhausting fatigue, and mental symptoms as well. This was all before FMS officially existed. As a child I was taken from doctor to doctor and throughout my life given many tests and medications. As you read in my book, about age 35 I stopped going to doctors because all they had to suggest was exploratory surgery and antibiotics...one didn't appeal to me and one made me feel worse. I was eventually diagnosed around 1990, after my younger sister had been. I was no longer seeking out treatment, I was sick of treatment. I knew I wasn't crazy and actually was lucky enough not to have met doctors who thought I was. But I also knew my case and symptoms baffled them and we were mutually frustrated. I had retreated from this frustration.

**HW:** What has worked best for you as a patient - the most effective treatment or combination of treatments you have utilized?

**CM:** I have been taking guaifenesin since 1995. Guaifenesin gradually got rid of my symptoms and allowed me to exercise, sleep better and rebuild my strength (mental and physical) and my life. It was not a magic pill, I don't believe there is one. Most of us have a lot of reconditioning and restructuring and proactive things we have to do in combination with treatment. But guaifenesin was the tool that allowed me to start this journey.

**HW:** As a medical assistant for FM patients, what is the most valuable thing you have learned about FM patients, or about FM in general?

**CM:** The dedication to my book sums this up best "You are braver than you believe, stronger than you seem and smarter than you think." Fibromyalgics show me every day how strong and brave and inspirational human beings can be. Too many have learned to doubt themselves, their senses, their instincts. I have learned that most of us are strong, incredible people though we may not see it in ourselves. Through this I have learned just how demoralizing FMS can be. I am lucky: a day never goes by that I am not touched, inspired, or grateful for my role in their lives.

**HW:** As a counselor, what is the biggest mistake you see FM patients make? How do you help them correct it?

**CM:** The biggest mistake I see people make are uninformed choices. Partially I blame the industries that crank out miracle cures and infomercials. I find too many people unable to distinguish between advertising and science. Partially I blame the part of each of us that wants the world to bring a solution to our door. There is no one thing that is going to help us all. I work hard to help people learn to evaluate

*Teitelbaum, M.D., continued from page 5...*

The point, says Teitelbaum, is to provide patients with "as many options as possible." He calls the educational program a "computerized CFS/fibromyalgia specialist." The program will analyze your medical history and, if available, lab tests to create a detailed medical record of your case for your physician; analyze your history and lab tests to determine which of more than 50 common factors that contribute to your illness are active in your case (most people have at least 5-6 factors); list the treatments (both natural treatments you can start on your own and prescription treatments you can encourage your physician to prescribe for you) that are most likely to help you (in order of priority) with directions on how to use them; and give you a printout of about 60 pages of information sheets tailored to your case and underlying diagnoses.

"It's like a book tailored to your personal case," he says. "This will allow your physician to treat you in the limited amount of time that he has available, because everything's all set out for him, making both diagnosis and treatment easier." Because the program cost more than a half a million dollars in time and money to develop, as well as thousands of dollars a month to maintain, he charges a fee to use it - \$160. "We've kept the price reasonable," he said. "We also want it to be available to everyone, so patients on Medicaid can use it for free." For those who aren't looking for a thorough medical evaluation and who would simply like to know how to treat their CFS and FM effectively, the website offers a shortened version of the regular program which takes about 25 minutes instead of two hours and costs \$88. "It still determines which treatments are most likely to help you and supplies detailed directions," says Dr. Teitelbaum.

Seemingly tireless in his mission to help CFS and FM patients around the world, Dr. Teitelbaum has written a new book - *Three Steps to Happiness: Healing through Joy* (Deva Press, 2003). "This book is about being happy," he said. "I wrote it to help people find out how to regain their life, to make a stand for themselves, to be who they are, and not care what anybody else thinks, to 'follow their bliss.'" **HW**

For more information:

Dr. Teitelbaum's website: [www.endfatigue.com](http://www.endfatigue.com).  
Dr. Teitelbaum's office telephone: 410-266-6958;  
Toll-free number: 800-333-5287.

*Editor's Note: From *Fatigued to Fantastic* and *Three Steps to Happiness: Healing through Joy* are available at [www.ImmuneSupport.com/shop/books.cfm](http://www.ImmuneSupport.com/shop/books.cfm) and at Dr. Teitelbaum's website.*

the plethora of information they receive from spam to books and blurbs in newspapers, to things a friend told a neighbor of theirs might help. I understand that fibromyalgics are desperate to feel better. I say this with compassion and I have walked in their shoes.

I try to teach people to LOOK at the information and the source. I urge them to try one thing at a time. Also to be reasonable about expectations. For fibromyalgics getting better is hard work. And I try to inspire them to understand that it is worth it. That sounds silly, doesn't it? But so many fibromyalgics have been sick for so long that they are not sure it's even worth the trouble it will take to beat the disease. They don't remember how wonderful life is without pain, without fatigue or depression or loneliness.

**HW:** The book excerpt that follows is from a chapter about exercise. Do you have any introductory comments you'd like to make? I know exercise can be a controversial issue for FM patients.

**CM:** I'll just give you a truthful vignette. When I was sick I was utterly convinced that telling patients to exercise was a well-orchestrated plot on the part of the medical profession. I firmly believed that doctors

told patients to exercise because they knew they couldn't. Then, in a month when they came back and complained they did not feel better the doc could take the high moral ground. "Well, did you exercise like I told you? No. Well, how on earth do you expect to feel better if you don't do what I say?"

But then I began reading medical journals to learn more about my illness. And a funny thing happened. Every study of exercise and FMS showed that it helped. Go to Medline [www.ncbi.nlm.nih.gov/PubMed/] and enter the search keywords 'Exercise and FMS.' The results will give you study after study after study. Weight training, aerobic exercise, walking, you name it, it helps. About the same time I became frightened of osteoporosis. So I started walking. No one hated the idea more than I did. And at first it did not make me feel physically better, only mentally proud of myself. Then getting up and getting out was something I looked forward to. Then I started accomplishing goals and also simply not panicking when I had to park far away from a store. I knew I could walk that far. It was a process. And I do know it helps, and on many levels. I know about the awful apathy of FMS, the inability to budge, to get up and turn off the TV. But I also know exercise is an integral part of the process of feeling better.

*Editor's Note: The following is an excerpt from "Week 4: Exercise Can Heal You" of A Patient-Expert Walks You Through Everything You Need to Learn and Do: The First Year - Fibromyalgia.*

### Exercise Can Heal You

Yes, you're tired. And yes, you ache. Undoubtedly, you won't be able to tackle your gym's new power spinning class or sign up for the local 10K run. But that doesn't change the fact that exercise is essential to your well-being. More than any other thing that you can do for your fibromyalgia, exercise will help you lead a more normal life. If you've ever wished for something you could do to change the face of your illness and its effects on your life - the answer lies here.

### The Strong Case for Exercise

Exercise releases endorphins (the body's natural painkillers), relieves stress, helps you maintain your weight, strengthens your muscles, protects your bones, and makes a healthier heart and lungs. Not only that, exercise will give you more energy and will also help you sleep better. Back in 1904, Sir William Gowers prescribed "perspiration" (or exercise) for his patients because in his experience it worked better than painkillers, a fact that has been corroborated over the years by many studies. The evidence is overwhelming that exercise will help you feel better. Yet most of us fight it tooth and nail. I know this because I did: tooth, nail, and with both hands and feet. I was dragged kicking and screaming to exercise, and I still don't love it. But like many other fibromyalgics, I do it. I'm a believer - I know it does what it's supposed to do.

### Take Small, Positive Steps to Start

In the beginning, it's not a good idea to set a certain amount of time as a goal. Thirty minutes can seem like thirty hours if you haven't slept in two nights and your feet hurt. Checking your watch will really be discouraging. So don't start with thirty minutes. Start with a reasonable distance. Down to the corner and back, around the block, over to the park - whatever distance seems within your reach in the beginning. Something is better than nothing, and doing something enough times will teach you that you can do anything. Remember to stretch your muscles before you start any sort of exercise, and be sure to respect your body when it signals a different kind of pain than you're accustomed to experiencing.

### Walking

For fibromyalgics (and most everyone else), the best exercise to begin with is probably walking. It's a lot safer for your joints than running. Though a warm pool and water aerobics may seem more inviting, swimming should be done only in addition to a walking program unless

you have something seriously wrong with your legs or back, that is, something other than fibromyalgia. The reason I'm saying this is that weight-bearing exercise is important for women, especially during perimenopause or menopause and after.

### Make Your Routine Easy

It is, however, important that you select a form of exercise that appeals to you. For most people it's harder to get motivated if they have to get dressed and drive to the gym and avoid the times when it's crowded with enthusiastic young people trying to impress each other. It's too easy to postpone the trip and to make excuses. That's why walking around where you live is a good way to start. If you live in a climate where walking outdoors isn't feasible year-round, you might consider investing in a low-intensity exercise videotape so you can work out inside your home. You might also want to try a treadmill or an exercise bike. Before you purchase any equipment, rent it for a while and see if you like it. And because most people don't take this advice, you can also find used equipment of every description in your local paper or on the Internet for very reasonable prices.



### Consider How You Feel

If you decide to start with walking, you won't need any special equipment, you won't have to pay a fee, and you can just get up and get started without any preparation or fanfare. Each day you can tailor your distance to your physical abilities. You can do it alone if you feel like being alone, or you can do it with a friend as a scheduled event. The latter is an excellent idea for at least one or two days a week.

### Pace Yourself

With fibromyalgia, pacing is always the key to every endeavor. Even though you can push yourself to do more, don't do it. Your goal should be, in the beginning, to walk at least every other day. This keeps your muscles from tightening up too much and will actually make exercise easier. Remember that if you overdo it, muscle soreness will not appear until 24 hours following the activity and peaks between two and three days later. Fatigue, of course, will occur sooner. A good workout will release enough endorphins to last 24 hours. This is why small walks more frequently is more beneficial for out-of-shape muscles. If you find you're too sore to walk when the scheduled day arrives, you'll know that you did too much. But always start out anyway. Fifty percent of the time you'll feel better once you get started and can talk yourself into continuing. The other half of the time you'll know it's just too much and you can do a little less. Sometimes if you feel achy, a warm shower before you head out can loosen you up, especially in cold weather. Be realistic, though, and understand that you will have setbacks and that you won't progress in a straight line to feeling better. You will move forward, though, if you stick with it.

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### It's Crucial to Warm Up Slowly

Before you start your exercise, you'll want to do some gentle warm-up stretching. Fibromyalgic muscles are tight so they're vulnerable to strains and sprains. Warming up means starting at a slower than usual pace. This allows your body to switch from anaerobic to aerobic exercise comfortably and smoothly. You don't want to contend with muscle cramps. So for the first five minutes of your walk, go slowly. If you're swimming or riding a bicycle, the same applies.

### Track Your Progress

Keep track on a little calendar or jot down on a sheet of paper how long you've walked each day. This way, you'll be able to see when you've done too much and suffered for it the next day. You'll also see how your workouts lengthen until you reach your goal. Concentrate on building up the duration of your exercise before increasing the intensity. When you reach the point where you are exercising the optimum amount, it will be up to you to decide whether to do more or just keep it up. You could graduate to a low-impact aerobics class, for example. Thirty minutes of moderate exercise a day will give you the benefits you need for your general health, but bear in mind that is the minimum amount of time. Once you have established your exercise program, it gets easier to continue. Your body will reward you by producing endorphins, your muscles (including your heart) will get stronger, and you will feel better and more competent. Succeeding at something as difficult as exercise, especially when you're tired and achy, will certainly improve your attitude.

### Balancing Your Exercise Routine

There are two basic types of exercise, and eventually you'll want to try to do both on a regular basis, although the regular basis for some things might be once a month. Aerobic exercise is the activity we started with because it makes your cardiovascular system stronger. Your body requires extra oxygen for this kind of work, requiring your heart to beat faster and pump more blood around your body. The more you exercise, the more efficiently your body will learn to deliver this extra oxygen, and will strengthen your heart muscle. This type of exercise is what builds stamina, which becomes very important when you need to function and you don't feel well. Walking, running, and swimming are examples of aerobic exercise.

Anaerobic exercise is the short, intense type of activity that doesn't require extra oxygen - there isn't enough time to get it from your lungs to your muscles. Instead it uses the small amount of fuels stored within the muscles. Weightlifting, push ups, sit ups, and short sprints are examples of anaerobic exercise. This is the kind of exercise you might want to do later on, when you feel better, to build or tone muscles for a better appearance. If you bear in mind the distinctions between the two types of exercise, you'll understand why you need to warm up before you start a session. If you start too vigorously, you'll be doing anaerobic exercise, and you'll get tired very quickly. This is because it makes time for the increased oxygen you're consuming to get to the muscles. It takes a few minutes for the body to switch into the aerobic mode where sustained exercise is easily fueled by oxygen, and after twenty minutes, fat.

### Flexibility Exercises

You may also want to work on improving your flexibility if your muscles get stiff. You should have a stretching routine for the times when your muscles tighten up. Some people do gentle stretching just before bed and in the morning after a hot shower. They find this makes them much more comfortable during the day. Another good time for gently stretching is after aerobic exercise, because your muscles are already warmed up.

### Stretch Your Muscles Carefully

The more stretching you do, the more you'll lengthen your muscles. You should aim to stretch at least four times a week. All stretching



movement should be done very slowly to the point where you feel gentle tension. When you feel this tension you should start to work up to holding this position for 30 seconds. Do not bounce when you stretch because this will trigger your muscle to contract. If you feel sharp pain, ease up a little, and stop the stretch that is hurting you if necessary.

### You Must Take Charge of Your Exercise Program

The truth is you can do more to relieve your fibromyalgia than any doctor. Exercise is one modality that, if done correctly, will improve the quality of your life. Healthy exercise is not a high-maintenance endeavor; it is a process that you can tailor to suit your abilities, and meld into the time you have available. If you want to feel better, you have to do it. Working with others in your support group or in special classes is a good way to feel solidarity and companionship on your journey with chronic illness. But the beauty is that you can do it any way you like. If you prefer to work alone, that too is an option.

**In a Sentence:** Exercise is one of the most important things you can do for your health when you have fibromyalgia. HW

*Editor's Note: To purchase Claudia Marek's book from which the preceding excerpt was taken: *The First Year--Fibromyalgia: An Essential Guide for the Newly Diagnosed (The First Year Series)*, visit [www.ImmuneSupport.com/shop/books.cfm](http://www.ImmuneSupport.com/shop/books.cfm). If you would like to contact Ms. Marek, you may do so by writing to: Att'n: Claudia Craig Marek, 4560 Admiralty Way, Suite 355, Marina del Rey, CA 90292, or by emailing [c.marek@fibromyalgiatreatment.com](mailto:c.marek@fibromyalgiatreatment.com).*

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# Tips From an Attorney: Win Your Disability Case by Obtaining Your Personnel File From Work

By Scott E. Davis, Esq.



*Scott E. Davis is a social security and long-term disability insurance attorney based in Phoenix, Arizona.*

Sometimes as a disability lawyer, one must be more creative than usual in order to win a client's disability claim. Such a situation presented itself recently in, of all places, the city of creativity, Las Vegas, Nevada.

I am blessed with a great practice as I have the opportunity to represent very honest, hard working people throughout the United States who are unable to work. I am fond of saying that we represent people who have good cases to begin with...our job is to make them better. However, occasionally a client's case does not "come together" the way we had hoped. This problem manifests itself in many different ways. It can be the treating doctor who does not want to help, or the medical records are of poor quality, are illegible, or do not assist anyone in understanding the severity of the client's medical conditions.

Unfortunately for my client in Las Vegas, a number of things fell apart in her case - we were left with scant evidence. In fact, two doctors (worker's compensation and social security) opined she could work during the same time she alleged she became disabled. At 32 years old, her age was not on our side. Quite frankly, the outcome on her case looked grim. However, I've learned when a case does not come together one must get creative and dig deeper rather than quit. While reviewing the file before the hearing I asked myself, "How in the world are we going to win this case?" Suddenly, I ran across the proverbial Golden Nugget in the case. Had we turned an apparent empty hand into a Royal Flush?

Let me break the suspense...my client with fibromyalgia and chronic migraine headaches won her case. Although I have traveled throughout the country and seen a lot happen at hearings, I was amazed at what transpired. At the hearing, this evidence roared like the MGM Hotel's Lion. What was it? The client's personnel file from a job she was fired from five years before she became disabled. How in the world was this even relevant if she managed to work for years after this? Many SSA bureaucrats and judges would not look at this evidence due to that fact ...but this judge did.

The personnel file was relevant because it corroborated her story. As stated, she was disabled due to chronic pain from fibromyalgia and migraine headaches. She testified at the hearing she was fired from "many jobs" due to poor attendance and productivity problems. One can testify to anything at a hearing; but it's a whole other blackjack game when you have documents corroborating your testimony. Her personnel file contained a "warning letter" and "termination letter" two months later for excessive absences; due to...you guessed it...migraine headaches. There was also a letter from her treating doctor asking the company to accommodate her medical problems, as he explained her medical problems were genuine and would cause her to miss work.

The company documented she was missing work over 30% of the time prior to and after the warning letter. For two months following the warning letter her attendance problems continued. The inevitable termination letter offered condolences, but also documented the significant negative impact her problems were having on this small company. The company explained it needed an employee who was "reliable." The letter was perfect evidence to support a disability claim. At the hearing, I quickly referenced the personnel file and the

judge made it clear he was indeed very impressed with it. I developed testimony from my client about how the problem did not resolve over the ensuing five year period, resulting in several more job terminations and the filing of a disability claim.

The judge was candid with me following the hearing as he explained he was not impressed with the case as there were many problems. I agreed. But 10 minutes after the hearing began, it was over. You should be aware this is not the first time a client of mine has won their case using primarily a personnel file. Follow these tips to get the most out of your personnel file and evidence you submit in your disability claim.



## 1. How to obtain your personnel file

First, it is obvious you must obtain the file. This may be as simple as sending a letter or authorization to release records to your former employer. But beware, many companies are reluctant to part with this information due to concerns over you suing them for various reasons including the failure to accommodate you under the Americans with Disabilities Act (ADA). Ameliorate this fear by telling them why you want it - that usually works. I usually have my client ask for the file because if I call, an alarm goes off. Try to turn on the charm and deal directly with the human resources department; if the corporate bean counters get involved, or worse, their lawyers, you'll likely never see the file.

If the company says "No" you've got a problem unless your disability claim is pending a hearing before a judge. This is because you lack subpoena power; you can't force the company to turn it over. But, upon a showing to the judge why the file is relevant, you can ask him/her to issue a subpoena and the company should comply. Only get the judge involved if you are certain the file contains (or should contain) evidence that advances your disability case.

## 2. What you're looking for in the personnel file

The things I look for are attendance records, records documenting how much sick leave has been used, warning letters regarding performance problems and job evaluations. Rarely does a personnel file contain all these potential "Golden Nuggets," but most will contain at least one if you documented your problems while working. Often an employee's job evaluations will begin to deteriorate toward the tail end of employment. However, good evaluations are relevant as they bolster your credibility when you testify that you enjoyed working and would like to return if only you could. If there is good evidence in the file, then submit it to SSA and/or the judge.

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### 3. How to document your personnel file

This is a very delicate issue, and I am not an employment law attorney. There is a fine line between documenting your personnel file with your medical problems while working, and creating your demise by losing your job. However, if you are sure you are unable to continue working and plan on filing a disability claim, I think it is prudent to document your problems. If you are missing time from work or are having problems functioning due to a medical problem, get that into your personnel file. If you are exhausting your vacation or sick time, let the company know why. Get a letter from your doctor to address the reasons for your absences. Once confronted with this documentation, most companies will likely go out of their way to accommodate your medical condition and special needs, at least for a period of time.

Remember, in a disability claim, you should always try to have another independent source corroborating the story about your trials and tribulations which led to your inability to work. Affidavits are one source of evidence and I encourage you to view your personnel file as another means to this end. Best of luck in pursuing your disability claim and remember, never quit! HW

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own intramuscular injections, and the best formulation I have evolved over time that I feel has given the best clinical results in my practice is a specialized Vitamin B12 injection as a combination of Heptaminol. I have this compounded by a pharmacy and it includes trace amounts of the mineral Selenium to help with the immune system, ATP and AMP to help with the energy system, Vitamin B12, and a special injectable formulation of Potassium and Magnesium Aspartate. Generally, I have patients use this formulation in the following scenario: 1-2 cc IM daily for 2 weeks, 3 times a week for 2 weeks, and twice weekly for 2 weeks, and then on an as-needed basis thereafter.

In addition, I found combinations of the oral supplements Enada NADH (1-4 daily) coupled with Effer-C and oral Potassium and Magnesium Aspartate to be very helpful. Obviously, we also need to look at the underlying etiologies as we evolve a more clear diagnostic picture individualized to the patient, and these will include evaluating for toxin overload, metabolic problems, nutritional deficiency, hormone imbalance, subclinical hypothyroidism, and chronic infections to name a few.

**ImmuneSupport.com:** On the topic of the immune system, what adjunctive therapies are you observing to be the most promising?

**Dr. Guyer:** For those who have a chronic viral infection, the combination I have liked mostly is the oral antiviral medicine, Famvir, which will often need to be continued for several weeks at a time. In addition, I have been using Isoprinosine 500 mg (2-6 daily) as an immune system adjunct. This is a semi-natural preparation that is manufactured by Newport Pharmaceuticals in Ireland, and at this time it is unavailable in the United States, but is easy to obtain with a doctor's prescription from Canadian pharmacies. In addition, I have these patients take Transfer Factor - often 2-6 tablets daily, and also NT Factor and ImmunPlex undenatured whey protein. This combined effort approaches and supports the immune system from multiple directions, and I have seen this therapeutic regimen deliver some of the best benefits for my patients.

**ImmuneSupport.com:** One of the common issues - particularly associated with fibromyalgia syndrome, is chronic pain. What are some avenues you have found useful in that regard?

**Dr. Guyer:** For chronic pain, a predominant complication for many sufferers, it is important to engineer a specific regimen that helps the individual patient in efficaciously getting out of the chronic pain cycle. When this is established, continued progress in more optimal health is possible.



One inclusion that I previously mentioned is the Cuddle Ewe mattress pad, which I have found is very helpful for many sufferers in reducing some of the chronic nighttime pain. In addition, there are prescription medicines I have found particularly helpful, such as low dose Lithium. This I generally use at about 150-300 mg daily which is significantly less than average doses used to treat neuropsychiatric problems, and at these low doses I have never seen any patient have side effects. Also, Guaifenesin is often very helpful, and I have seen a number of patients who previously required narcotic pain medicines get off those pharmaceutical approaches just by taking Guaifenesin. In addition, Dextromethorphan at low doses, particularly at night, are often helpful, and for those who have chronic pain and low energy, Ritalin in low doses I have often found very helpful. In addition, in our office we use combinations of Neural Therapy and trigger point injections very effectively (for those interested in learning more about Neural Therapy, refer to [www.NeuralTherapy.com](http://www.NeuralTherapy.com)).

**ImmuneSupport.com:** Regarding the mood disorders that frequently plague CFS and FM sufferers, what is helpful?

**Dr. Guyer:** Many of the other components I previously mentioned will usually help a patient manage these symptoms, primarily Insulin Potentiation Therapy [to read about Insulin Potentiation Therapy, please visit [www.ImmuneSupport.com/library/showarticle.cfm/id/4485/searchtext/4885/](http://www.ImmuneSupport.com/library/showarticle.cfm/id/4485/searchtext/4885/)]. For those who tend to be chronically depressed, I believe this therapy is wonderfully effective. Other components of the anxiety-depression problem often relate to hormonal balance. Many patients with a deficient or a subclinically deficient thyroid status will often be depressed and anxious, and as those elements are treated and improved - often with thyroid replacement therapy, that patient will feel immensely better. In many instances, I have seen patients who have been chronically fatigued

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for 20-30 years who tried various antidepressants with minimal results respond remarkably to replacement doses of Armour Thyroid or Sustained Release Micronized T3 (the active thyroid hormone).

Also, I have seen very good success, particularly with anxiety, using the Alpha-Stim SCS, which is an FDA-approved electrical device that can be used by the patient at home. It has portable electrodes that can be adhesively applied to the scalp for 20-30 minutes daily. It tends to be very helpful for chronic pain and acute pain issues as well as anxiety and depression, in addition to improving sleep for many patients. I have seen very good success with this therapy, and for many patients, their insurance will actually pay for it. (You can look up information on the Alpha-Stim unit at ImmuneSupport.com and at Alpha-Stim.com).

With these issues, one must also look 'situationally' and often there are life circumstances which contribute to ongoing chronic depression and anxiety. This can be one of the tougher problems to navigate as many individuals, while willing to be treated for perceived biochemical anomalies with nutrients and medicines, are often reluctant to pursue getting help and support for some of their emotional needs. Therefore, I try to provide an open and supportive forum for patients to discuss their feelings and to encourage working with a process that is uplifting for them. For many this will be working with a well-trained counselor, or it may be dialogues with their spiritual leader (like a church pastor or rabbi), or it may be merely walking their dog every evening. We all have personal uplifting things we turn to in our lives, whether musical (my favorite is "Amazing Grace" sung by Elvis Presley), or hobbies, or other outlets that help infuse us with a sense of purpose, faith and hope. In any event, it is important to define what those are to each person and include them in the overall treatment plan.

**ImmuneSupport.com:** Other problems CFS and FM patients experience are irritable bowel symptoms, poor digestion, gas and bloating (particularly after eating), and overall poor nutrient absorption. What are some of the primary contributors to such problems, and what treatments have you found to be most helpful?

**Dr. Guyer:** 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 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 comprehensive digestive stool analysis (Great Smokies Diagnostic Laboratory performs such analyses).

If yeast organisms are noted on the comprehensive digestive stool analysis, 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. Again, 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 functions, 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 Phosphatidyl Choline.



**ImmuneSupport.com:** Thank you for your time and insights, Dr. Guyer. One final question - what newer therapies are you beginning to use in your practice that you believe show significant promise for adjunctively treating CFS and FM?

**Dr. Guyer:** I have been particularly interested in Dr. Shoemaker's work with the hormone MSH. He has been kind enough to discuss his research with me on several occasions, and indeed it is intriguing that MSH is often an overlooked hormone in medical therapeutics, as there are several thousand published studies on this hormone that can be viewed on the National Library of Congress database. It seems to possess significant immunomodulatory and anti-inflammatory activity and we are initially starting a first phase on using intranasal MSH adjunctively with 3 patients, and I am anxious to see how they will do with this relatively new therapy.

In addition, I have been particularly pleased with the glandular therapies - especially in injectable form, particularly for the adrenal and mesenchyme preparations, and the long term benefits in rehabilitation potential at the cellular level seem to be significant, and probably to some degree represent a therapeutic option that is fairly close to the promise of stem cell therapy. HW

*Editor's Note: For additional information, contact Dr. Guyer through his website at [www.DaleGuyerMD.com](http://www.DaleGuyerMD.com).*

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# Pioneering Treatments for Fibromyalgia & Chronic Fatigue Syndrome

By Rosalie Devonshire, M.S.W., and Julie Kelly, M.S., R.N.

*Rosalie Devonshire, M.S.W., is a former teacher, FMS and CFIDS patient, who works clinically with individuals and families facing non-medical difficulties and provides stress management, biofeedback and psychotherapy treatment to those with physical illness. Julie Kelly, M.S., R.N., is a fibromyalgia nurse clinician at Abbott Northwestern Hospital in Minneapolis, Minnesota. She works with FM patients and their family members in a multidisciplinary treatment program and educates a variety of health professionals on the diagnosis and treatment of FM.*

There are some physicians who have been treating Fibromyalgia Syndrome (FMS) patients by using therapies which could be described as "experimental." We would like to share with you information from a few of the more widely recognized physicians performing this type of pioneering work, because we feel that this information should be freely accessible to all FMS sufferers. If you choose to try some of these therapies, you might have to find a physician in your area willing to accommodate you. Remember that trying a novel therapy should be done with extreme caution.

Dr. Jacob Teitelbaum is one physician performing pioneering work. He suffered from CFIDS and FMS [which he claims to have overcome] and knows firsthand how it affects someone. Dr. Teitelbaum uses various laboratory diagnostic tests to assess a number of problems he feels contribute to FMS and CFIDS. After he takes a complete history, he may treat you with some or all of the following: synthroid or armour thyroid to boost a low thyroid level, cortef for adrenal insufficiency, DHEA to boost DHEA levels, medications to treat neurally mediated hypotension which causes dizziness, oxytocin (a female hormone), estrogen and progesterone, various vitamins, antidepressants, herbals for sleep aids, anti-yeast treatments, stool parasite therapies, homeopathics and various other medications such as nitroglycerin, naphazoline hydrochloride (eye drops), calcium channel blockers, and others.

Dr. Teitelbaum's treatment program has benefited many patients and takes into account that FMS symptoms may be caused by a combination of factors. You may want to purchase his book (*From Fatigued to Fantastic*) and share it with your physician, who might be interested in trying some of the treatments he employs.

Dr. Jay Goldstein [retired in 2003] is another pioneering physician and researcher. He has treated FMS and CFIDS patients for over 15 years and has written a book geared for the physician called *Betrayal By the Brain: The Neurologic Basis of Chronic Fatigue Syndrome, Fibromyalgia Syndrome and Related Neural Network Disorders*. There is a companion book written by a patient for patients, which is called *A Companion Volume to Dr. Jay A. Goldstein's Betrayal By the Brain*, by Katie Courmel. His treatment protocol differs substantially from those who use medications to alleviate only specific symptoms, such as low serotonin levels. He believes FMS and CFIDS patients suffer from problems in the way their brains process sensory input from noise, lights, odors, pain, food, medications and chemicals. By a complex mechanism involving various brain chemicals, our brain interprets information it receives from our environment, filters out appropriate and inappropriate information, and tells our body how to handle the input. Dr. Goldstein feels our brains are misinterpreting the information, resulting in an amplification of pain signals, odors, and other sensations. Just going to the local mall bombards our senses with so much stimuli it can prove exhausting. This "wears" out the brain and can cause the cognitive problems many patients experience.

Dr. Goldstein believes FMS and CFIDS patients have a genetic predisposition for developing these syndromes. Developmental issues, in which one feels unsafe for a period of time causing a hypervigilant attitude, can change the way the brain responds to stimulus; exposure to viruses, severe emotional stress and exposure to environmental stressors, are all factors in the development of these syndromes. Some people may be particularly strong in their genetic predisposition and will develop these syndromes no matter what their stressors may be, while others need a variety of these stressors to occur before they will develop FMS or CFIDS. Dr. Goldstein treated his patients in a very different manner than other physicians. [Editor's note: To read more about Dr. Goldstein's treatment protocol, visit [www.ImmuneSupport.com/library/showarticle.cfm/ID/4351](http://www.ImmuneSupport.com/library/showarticle.cfm/ID/4351)] You will note that he used a variety of medications. Once again, your own physician might be interested in trying his treatment protocol.

## Specific Treatments

### Oxytocin - DHEA - Nitroglycerin

Another therapy that has proven beneficial to some patients in conjunction with other treatments described is that used by Jorge Flechas, M.D., Jay Goldstein, M.D., and Jacob Teitelbaum, M.D. DHEA levels are found to be low in FMS patients. By carefully listening to his patients' complaints, Dr. Flechas decided that the hormone oxytocin, along with DHEA supplementation, might help alleviate some of his patients' symptoms. He first runs a blood test to determine baseline DHEA levels, then adds supplements to bring levels up to what they should be naturally around age 30 (150-200 mcg/dl); 25-30 mg of DHEA is recommended, either in capsule form or cream. Dosages and duration of usage should be determined by a physician. Checking estrogen and testosterone levels is also recommended.



Once your DHEA is up to optimal levels, Dr. Flechas puts his patients on a 10 ml injection of oxytocin. Oftentimes patients will notice a flushed feeling in their hands or face immediately after the injection, which may or may not last for more than a few minutes. Positive effects will take approximately two weeks. Dr. Flechas recommends taking supplements of choline and inositol to increase the effectiveness of the oxytocin. Nitroglycerin is another medication he adds to his regime to enhance pain relief. Patients who benefit from this treatment often have cold hands and feet and are pale. Daily injections of oxytocin can be given, or there is a capsule available from pharmacies. Dr. Goldstein believes injections are more effective.

Not much has been written about oxytocin in the medical literature, but it is known to have a role in inducing labor in pregnant women, facilitating the let-down response in lactating women, and regulating blood circulation in the small vessels of the body. This hormone works

within a complex network of other chemicals in our bodies that have been found to be dysregulated, such as neuropeptide Y, corticotropin releasing hormone (CRH), thyroid hormone, estrogen, DHEA, and others. Two potential side effects are weight gain and water retention. No studies have been performed on this hormone treatment as of yet [2001], but will hopefully be forthcoming.

#### **Atenol - Florinef - Increase Salt and Water Intake for Neurally Mediated Hypotension**

If you are troubled by dizziness and/or fainting spells, you might want to speak to your physician about the possibility of having a cardiologist perform a tilt-table test. During the test you are strapped to a table and turned 70 degrees so that your legs are close to the floor but do not touch it. Normally, when you get up from a sitting position your brain signals your blood pressure to perform properly when your feet touch the ground. Researchers have found that CFIDS patients and some FMS patients have a dysfunction in the regulation of this system and their blood pressure drops significantly, causing improper blood flow to the brain. This dysfunction can lead to feelings of fatigue and other symptoms associated with CFIDS/FMS. These tests were originally performed by Johns Hopkins University researchers and replicated by Daniel Clauw, M.D. A natural treatment for this problem consists of increasing salt intake and drinking lots of water. Some physicians prescribe atenolol (Tenormin), a beta blocker, or Florinef (fludrocortisone), an adrenal steroid. These drugs do have side effects which your physician should make you aware of.

You could have this condition even if you do not have low blood pressure or a history of fainting or dizziness. This treatment is well worth pursuing and might be a good addition to your overall program.

#### **Intravenous Ketamine**

One study using intravenous morphine, lidocaine and ketamine showed that ketamine proved to be the most effective in reducing pain levels. Morphine, an opioid, did not help at all in this study; lidocaine, an anesthetic used in trigger point injections, was somewhat helpful; and ketamine, an NMDA pain receptor antagonist, decreased pain and had a longer lasting effect than the others. With its promising results, this study could help lead researchers to other drugs which affect the NMDA receptors and possibly help alleviate pain for FMS patients.



#### **Anti-Yeast Treatments**

Some physicians and holistic practitioners believe there is an underlying yeast problem contributing to FMS/CFIDS symptoms. The most common yeast, *Candida albicans*, is thought to be the culprit. Finding a physician to treat yeast problems can be difficult, however. Many holistic doctors treat for *Candida*, as do many nutritionists and Chinese medicine doctors. Nutritionists cannot prescribe anti-fungal medications but will use various herbs and vitamin supplements as well as suggest changes in diet to help alleviate yeast overgrowth. Some physicians, such as Jacob Teitelbaum, M.D., use both to rid patients of yeast overgrowth.

Our bodies naturally have yeast living in harmony with friendly bacteria inside our bodies. Yeast are there to help our bodies in various ways, but sometimes the yeast overpower the "good bacteria" and cause a yeast invasion. This can occur after repeated courses of antibiotics. Yeast also thrive on sugar and yeast-laden foods such as cheese, bread, and wine. Giving up sugar and all sugar-containing products, including corn syrup, jelly and honey, is one recommendation for controlling a *Candida* overgrowth. Some practitioners recommend giving up all yeast-containing foods such as cheese, beer, wine, and bread. Others feel that giving up sugar alone is sufficient. Your body will most likely go through a withdrawal period in the first seven to ten days of a diet like this; you may even feel worse as the yeast die off because their source of "food" has been removed.

Many people are amazed how their craving for sugar decreases if they can abstain from it for just ten days. Believe it or not, you may not even want sugar anymore! It is also recommended to replace the friendly bacteria that have been lost, by taking acidophilus supplements or eating plain yogurt (without sugar) which contains live acidophilus cultures.

It is very important to read labels on all foods you buy if you choose to eliminate sugar. Many foods we buy today include sugar disguised as high fructose corn syrup, dextrose, and maltose. Many cereals are loaded with sugar, as are some breads. Shopping in a health food store or buying bread from a bread maker who only uses stone ground grains and adds no sugars is advised. Some grocery store chains are offering more sugar-free selections as consumers are becoming more health conscious. Remember, just because a label states "all natural" or "no artificial ingredients" does not mean the product hasn't been sweetened with fruit juices, which you may need to avoid, too. You may need six to twelve months on this diet to take care of the yeast overgrowth. That may sound like a long time, but it can be well worth the trouble if you feel better in the future.

Laboratory tests for detecting yeast overgrowth are not thought to be conclusive, so many practitioners use symptoms and questionnaires to determine whether or not the problems you are having are yeast



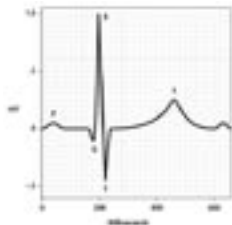
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[Devonshire, M.S.W., continued from page 13...](#)

related. Your physician can prescribe anti-fungal medications for you (commonly used to treat fungal overgrowth) including Diflucan, Sporanex, and Nystatin. The late William Crook, M.D., has written two books on yeast problems and treatments. [Editor's note: For those patients who decide against using prescription drugs or for whom such medications do not work or are not tolerated - a common problem among CFIDS and FMS patients - alternative treatment methods to consider for yeast overgrowth include nutritional support products like Yeast Rx.]

#### Biofeedback and EEG Treatment

Stuart Donaldson, Ph.D., of Calgary, Alberta, Canada, has been treating patients with a combination of biofeedback and EEG brain wave therapy, which uses no drugs and has shown to be helpful in reducing symptoms.



#### Balancing Dopamine and Serotonin

Daniel G. Malone, M.D., a rheumatologist at the University of Wisconsin, has been treating FMS patients with a combination of dopaminergic and serotonergic drugs including L-dopa, 5-HTP, Fenfluramine, Pemoline and phentermine. He found statistical improvement in 76 patients out of 122 using this protocol. Unfortunately, two of the medications he had been using, Fenfluramine and phentermine, have been withdrawn from the market because of serious heart-valve complications found in some patients who were taking these medications for weight loss.

#### Important Note

We believe these novel treatments are exciting to report because they add to the possibilities of treatments for improving your symptoms. Your physician may not know about all of these therapies, so it might be up to you to educate them. Dispensing this information to all physicians involved in FMS and CFIDS patients is important in providing helpful treatment. Because these treatments are so new, it is not known whether they are most beneficial when prescribed singly or in conjunction with other treatments. These treatments have not been subjected to [rigorous clinical] research as of yet [2001], and using them could be risky for you. It might be something you could look into, however, if the other, more researched treatments available have been tried and you still do not feel better. Many physicians feel a multidisciplinary treatment approach is necessary to control FMS [and CFIDS], which means using all, many, or some of the treatment options described in this book. At this time, we have more treatment options to choose from than we did a few years ago. HW

*Editor's note: The foregoing book excerpt is reprinted with permission from Taking Charge of Fibromyalgia: A Self-Management Program for Your Fibromyalgia Syndrome (published by Fibromyalgia Educational Systems, Inc.) which can be purchased from [www.ImmuneSupport.com/shop/books.cfm](http://www.ImmuneSupport.com/shop/books.cfm) or [www.fmsedsys.com](http://www.fmsedsys.com), where you can also learn more about the programs offered by Fibromyalgia Educational Systems.*



## Summary: Nancy Klimas M.D.'s Talk at the NIH Chronic Fatigue Syndrome Workshop

By Rich Van Konynenburg, Ph.D.

*Nancy Klimas, M.D., is a Professor of Medicine, Psychology, Microbiology and Immunology at the University of Miami School of Medicine. She is the Principal Investigator of one of the three NIH sponsored CFS Research Centers. She has conducted research on the immunology of CFS since the late 1980s. Her talk at the NIH CFS workshop on June 12, 2003, focused on the immune dysfunction observed in CFS. She reported on a critical review of the published papers in this field, presented what appeared to her to be the consensus of this work, discussed the problems with the existing data and the difficulties in measuring immunological parameters, and suggested guidelines for future efforts in this field.*

In summarizing the published work, the main conclusions she presented were that there are a lot of data indicating that there is chronic immune activation in CFS, that there is a fair amount of data demonstrating that there is a shift to a Th2 type of immune response, there is considerable data showing that there are changes in cytokine expression, and there are a lot of data showing lowered natural killer cell activity (low NK cell cytotoxicity). In addition, she noted that there is evidence for elevated numbers of immune complexes, elevated levels of antinuclear antibodies (ANA), higher prevalence of allergies, and an activated RNase-L pathway.

(Briefly, here's what these things mean: Chronic immune activation means that the T lymphocytes, a type of white blood cell that coordinates the activities of the immune system, show evidence that they have been alerted to the presence of a threat, and they continue to remain in this alerted state, whereas normally they would return to the inactivated state after the threat was defeated.

The shift to a Th2 immune response means that instead of maintaining a balance between a cell-mediated or Th1 type of immune response and a humoral or Th2 type of response, the immune system has shifted to a Th2 response and stays "locked into" this type of response. These two modes are both needed in order to have protection against both normal bacteria, which stay outside the human cells, and viruses and intracellular bacteria, which enter human cells. Th1 operates by killing infected human cells.

Th2 operates by making antibodies, which attach to normal bacteria and other pathogens that are outside human cells, so that they can be marked for killing by cells specialized for this job. Both are needed, but in CFS, the Th1 response is missing. Cytokines are chemical messengers that are made by white blood cells of various types to signal each other, in order to coordinate the overall immune response. They are also used to communicate from the immune system to parts of the brain. For example, some of them carry a signal to the hypothalamus to produce a fever. Different patterns of cytokine concentrations are found in the blood during Th1 and Th2 immune responses, and this is one way to identify the type of response that is dominant.

Immune complexes are combinations of antigens and antibodies that are joined together in a "clump." An antigen is usually a protein that is part of a virus or a bacteria, or something else that's "foreign." An antibody (also called an immunoglobulin) is a protein that is made to recognize a specific antigen and bind to it. Antinuclear antibodies are antibodies against the nuclei of human cells. Allergies are cases in which the immune system unfortunately responds against something that is not actually a threat.

The RNase-L pathway is a pathway in all cells that can be activated by viral infections or toxins and that results in destruction of messenger RNA, both that produced by viruses and that produced by the human cells themselves. Activation of this pathway is sort of a desperate move on the part of the cell to prevent the proliferation of viruses, while at the same time interfering with the ability of the cell to make its own proteins. It is analogous to an army firing artillery at its own soldiers' positions (hopefully they are in foxholes) in order to kill an enemy force that has overrun their positions.)

Nancy also noted that there is a correlation between immune parameters and symptoms. In particular, when low Natural Killer (NK) cell activity (Th1) and elevated T-cell activation (Th2) are combined together, they are found to correlate well with increased symptom severity. Patients with high cognitive difficulty are found to have high neopterin levels (Neopterin is produced by activated macrophages. A macrophage ("big swallower") is a type of cell that is able to engulf and digest another cell.)

Nancy also briefly mentioned the experiment in which her group removed lymphocytes from lymph nodes of PWCs, placed them in a culture designed to shift them to a Th1 type of immune response, and reinjected them into patients, successfully shifting the immune response temporarily away from Th2 in seven patients. Six of them exhibited significant improvement in cognitive function and fatigue for a while.

She also mentioned her group's work on PWCs who underwent the stress of Hurricane Andrew. This turned out to produce chronic stress for many people, because of severe damage to their houses (she mentioned roofs being blown off). They found that the PWCs who had lower cognitive difficulty also tended to have better immune function. Those with lower NK cell function also tended to have more severe fatigue and worse cognitive function.

Nancy also noted that her group has done some work to try to develop an understanding of the mechanism of the immune dysfunction. In particular, they have found that the NK cells in PWCs are low in perforin, which is the substance they normally use to punch holes in infected cells in order to inject granzymes to kill them.

Among the problems she mentioned with the existing data were that the populations studied were heterogeneous, were not well described, and were frequently too small for statistical significance to be achieved; the studies were performed over a period of about 15 years during which time the case definition for CFS changed; methodology was not standardized so that it is difficult to make comparisons between studies; the immune parameters change over the course of time because of remission relapse cycles, the monthly hormonal cycle in women, and the circadian rhythm, none of which were accounted for; and sufficient attention was not paid to the fact that immunological samples "do not travel well" and that the laboratories doing the analysis of samples must "know what they are doing."

For the future, she recommended longitudinal studies rather than cross sectional studies as were done in the past, and efforts to avoid these other problems noted in the past studies.

### Here's my view of the significance of the things Nancy discussed:

First, it is clear that immune dysfunction is present in at least a substantial subset of PWCs. While the cause of this dysfunction has not been clearly identified in a scientific sense, it seems very likely to me that it arises because of the body's response to long-term stressors, which is probably influenced by genetic variations in different people.

Long-term stress is known to act on the immune system via the

HPA axis and the sympathetic nervous system. I think this response involves an initial long-term increase in levels of glucocorticoids and catecholamines (adrenalin and noradrenalin), which is the normal response to stress. This is known to suppress the immune system, and particularly the Th1 immune response, which is essential for defending against viral, intracellular bacterial and fungal infections.

For reasons that are not yet understood, but which may involve genetic makeup, in some people this suppression is severe enough that the immune system becomes unable to mount a successful defense against endogenous viruses, intracellular bacteria, and fungi, such as yeasts. I suspect that this suppression involved depletion of glutathione (and cysteine), as a result of the detoxification of o-quinones resulting from the oxidation of the large amounts of catecholamines from the long-term stress response, as well as from other factors. Glutathione depletion has been observed and reported in CFS, and it is known to be another factor that can cause a shift away from Th1 and toward Th2.

Under this model, the observed immune system activation is explained as a response to the ongoing infections, which the immune system is unable to defeat. The shift to Th2 is explained initially by the long-term glucocorticoid elevation, and later by the glutathione depletion. The changes in cytokine expression reflect the shift to Th2 and the continued futile efforts of the immune system to organize itself to attack the infections.

The low NK cell cytotoxicity results from deficient perforin production, which in turn is caused by a shortage of cysteine, which occurs because of glutathione depletion. Perforin production requires large amounts of cysteine. Basically [to use a military analogy], the soldiers have no bullets, but their officers continue to shout orders to them to kill the enemy.

Under this model the elevated numbers of immune complexes would result from elevated production of antibodies from the Th2 shift, and elevated levels of antigens from the infections that are allowed to proliferate. The increased prevalence of allergies would also result from the Th2 shift, and probably the elevated ANA would as well. The activated RNase-L pathway occurs because of the failure of the Th1 immune response to appear and to defeat the intracellular infections. As Dr. Cheney has said, "the cavalry never arrives."

The correlation between the parameters describing the immune dysfunction and the severity of symptoms suggests that they have a common cause. I suggest that this common cause is the depletion of glutathione (and cysteine). I suggest that PWCs operate just at the ragged edge of not having enough glutathione for their systems to function. If anything occurs to further lower their glutathione supply, they suffer in several ways simultaneously, because several systems are at this "ragged edge." A large demand for glutathione will push them over the edge into a crash, and it will take some time to rebuild their supply.

I suggest that the reason Nancy and her group were able to switch immune cells to Th1 in culture is that they used a culture medium that contained sufficient cysteine, which the cells did not have when they were in the body. When they were placed back into the body, they were able to avoid the shift back to Th2 for a while, but eventually the lack of sufficient cysteine shifted them back.

I ask the readers to please be aware that my interpretations of the immunological studies are unproven hypotheses and are subject to change as more is learned. Nevertheless, I think they have some evidential basis, and if nothing else, they are at least an attempt to tie these scattered observations together into a coherent picture that has some degree of fit with the rest of the disease process. I firmly believe that it is important in research always to have a hypothesis to shoot at in order to make progress in understanding. **HW**

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