



A NEWSLETTER FOR PEOPLE WITH FIBROMYALGIA SYNDROME/CHRONIC FATIGUE SYNDROME

54TH EDITION

Celebrating our 13th Year

JULY 2001

DOCTOR, WE'VE GOT A PROBLEM...

How do you handle a physician who shoots down your therapeutic suggestions, or worse yet, doesn't even believe that your symptoms are real? Whether your diagnosis is fibromyalgia syndrome (FMS) or chronic fatigue syndrome (CFS), your symptoms are difficult to treat and neither diagnosis garners much understanding from physicians. Your doctor may try to help, but if you are stuck in a managed care system (i.e., HMO), does this also mean that you are forced to stick it out with a "gatekeeper" physician who has little or no experience in administering the most current therapies? We posed these questions to a number of counselors and received the following advice:

Gila Bastien, Ph.D., Berkeley, CA

My impression is that whatever the disease, the doctor and patient are a team. It will never work if your doctor is insensitive to your treatment ideas and needs. If you find that this is absolutely the case, get a new doctor!

Randy W. Martin, Ph.D., West Los Angeles, CA

If you think that your doctor might be receptive, give him or her literature to support your viewpoint about therapies and gently try to educate them. Depending upon the reception that you receive, you may want to change your HMO doctor. The best way to go about this is to ask your HMO to allow you to interview a few doctors. Then you can make a switch to a doctor that is more to your liking.

Bruce Eimer, Ph.D., a person with FMS and a clinical psychologist specializing in pain management and hypnosis therapy, Philadelphia, PA

If the physician is disrespectful, find another physician. Don't let yourself be abused by anyone. It's bad for your self-esteem, your ability to cope, and your FMS. Switch to another Primary Care Physician (PCP)—yes, you have the right to do so! If the doctor is an HMO gatekeeper, you can tell the doctor that you feel he or she is being insensitive to your needs and that you will not tolerate such treatment. HMO doctors care about their patient satisfaction ratings, which are tabulated by the HMOs. These ratings determine their bonuses and contract renewals. Let your doctor know that you are

going to report your dissatisfaction with the HMO.

It is best if your doctor gives you an opportunity to explain your reasons for wanting to try a particular treatment. HMO doctors are often "data-driven." Give the physician copies of any articles that summarize the rationale and research that lends support to the validity of your proposed treatments. However, it is important to demonstrate that you are willing to stick with a given treatment long enough to determine if it can help you or not (unless you have intolerable side effects which you should report to your treating doctor immediately!!). It is a bad idea to jump from treatment to treatment without giving each therapy an adequate trial. This is the only way that you can learn what might be causing your side effects or intended benefits.

If your doctor won't give you a rationale for his or her decisions, and is basically a DESPOT, the best thing you can do is change doctors. If you have been depending on this doctor for your disability documentation, this is all the more reason to switch, as you will probably sleep bet-



In This Issue...

NEW MODEL EXPLAINS FMS/CFS

Glia cells and pain	p. 3
Potential for test markers	p. 4
Two drugs in clinical trials	p. 4
Overlooked pain generators	p. 5
Handling doctor problems	p. 1
Recap of growth hormone studies	p. 6
Growth hormone Q&A with Dr. Bennett	p. 7
Medical journal reports - Part 1	p. 9
Health hype and help on the Internet	p. 10
Distinguishing FMS from MS	p. 10
Functional MRI scans revealing	p. 12
Brain SPECT scans compare FMS, CFS, depression, anxiety & healthy controls	p. 13
Minimizing your physician's fear of addiction ..	p. 14
Realistic benefits of exercise & new video	p. 15

PHYSICIANS FEARS OF ADDICTION

In the last issue, we commented that a physician's fears about prescribing opioids to addicts is the number one reason that chronic pain patients do not receive opioids to treat their pain. **Randall Oliver, M.D.**, of Evansville, IN, and a specialist in pain management, kindly responded to this article by giving advice on what FMS patients might expect from opioids, an explanation of the drug enforcement problems physicians face, and how patients might help their physician overcome their addiction fears.

- Oliver has roughly 500 FMS patients in his practice and has found that opioids don't work as well for this patient group compared to other musculoskeletal pain patients he treats. However, he does have a subgroup of FMS patients who obtain significant relief from opioids. For these patients, he is careful to not give a dose that will increase problems some people with FMS may have with this class of medications, such as difficulty concentrating, fatigue, insomnia, and depression. Oliver says it is not reasonable for FMS patients to think that opioids can decrease their pain levels down to zero. Instead, it's reasonable to hope for moderate pain control while using a dose that attempts to keep side effects at a minimum.

- The worry that physicians have about the Drug Enforcement Agency (DEA) is a real one, says Oliver. He recently gave a seminar and invited the local DEA representative to talk to the attendees about opioids and addiction. The representative's basic answer to physicians about how to stay out of trouble with the DEA was to "don't give opioids to drug addicts." The DEA agent gave no advice on how to determine who was a drug addict. The DEA's lack of useful advice places an unrealistic burden on physicians when it comes to scrutinizing their patients. (*Some physicians avoid this dilemma by simply saying NO to opioids for all their patients.*)

- How can FMS patients overcome these hurdles, so that they may be allowed a trial run of an opioid? Oliver says he has recently started using a substance abuse consulting agency in his town. Before prescribing an opioid to a patient, he has them get a consult with an agency well-versed in substance abuse counseling. I feel much more comfortable prescribing opioids if the consulting agency believes that the patient is at little risk for substance abuse, says Oliver. In addition, he believes that the consultation letter in his files benefits him should the DEA come knocking on his office door. It has also been his experience that drug addicts simply don't make the appointment and they never appear at his office again. So here is Dr. Oliver's advice to patients who have trouble with a physician who will not write them a prescription for opioids: offer to make an appointment with a substance abuse counselor ahead of your doctor's visit to make your physician feel more comfortable about prescribing you an opioid. **END**

Fibromyalgia Network

PO Bpx 31750

Tucson, AZ 85751-1750

TEL: 800-853-2929

FAX: 520-290-5550

www.fmnetnews.com

E-mail: fmnetter@msn.com

This article written by Dr. Oliver appeared in the July issue of the Fibromyalgia Network. Which is distributed to physicians and patients.

Fibromyalgia Network is a quarterly publication (Jan., April, July, and Oct.). Annual subscription rate is \$25. If you would like to subscribe please call the # above.