



National EMS Network Newsletter

Points of interest

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- **We do appreciate all the letters to the Editor and hope that you keep writing. We look forward to your letters and comments.**
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- **If you have not seen our web site yet, it's improved and holds a lot of information.**
- **CHECK OUT WWW.NEMSN.ORG**

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Irritable Bowel Syndrome

Contributed by the International Foundation for Functional Gastrointestinal Disorders (IFFGD)

Irritable bowel syndrome (IBS) is the most common functional gastrointestinal (GI) disorder with worldwide prevalence rates ranging from 9–23% and U.S. rates generally in the area of 10–15%. Functional disorders are conditions where there is an absence of structural or biochemical abnormalities on diagnostic tests, which could explain symptoms.

IBS is best understood as a long-term or recurrent (chronic) disorder of gastrointestinal functioning. It is characterized by multiple symptoms involving a disturbance in the regulation of bowel function that results in unusual sensitivity and muscle activity. These disturbances can produce symptoms of abdominal pain or discomfort, bloating or a sense of gaseousness, and altered bowel habits (diarrhea and/or constipation).

Many IBS patients also report non-gastrointestinal symptoms such as fatigue and muscle pain . . . these non-gastrointestinal symptoms may be due to IBS coexistence with another disease or condition, such as fibromyalgia . . .

Not all individuals with IBS symptoms seek medical care for their symptoms. Nevertheless, there are between 2.4 and 3.5 million annual physician visits for IBS in the United States alone. IBS is the most common disorder diagnosed by gastroenterologists (doctors who specialize in digestive diseases or disorders) and accounts for up to 12% of total visits to primary care providers. The cost to society in terms of direct medical expenses and indirect costs associated with loss of productivity and work absenteeism is considerable – estimates range from \$21 billion or more annually.

Symptoms of IBS

Abdominal pain and/or discomfort is the key symptom of IBS and is often relieved with the passing of a bowel movement (defecation). There are many causes for abdominal pain, but in IBS, the pain or discomfort is associated with a change in bowel habits. While everyone suffers from an occasional bowel disturbance, for those with IBS the symptoms are more severe, or occur more often – either continuously or off and on. IBS affects men and women of all ages.

Symptoms can vary and sometimes seem contradictory, such as alternating diarrhea and constipation. The intensity and location of abdominal pain in IBS are highly variable, even at different times within a single person. The symptoms of IBS are produced by abnormal functioning of the nerves and muscles of the bowel. In IBS there is no evidence of an organic disease (where structural or biochemical abnormalities are found), yet, something – a “dysregulation” between the brain, the gut, and the central nervous system – causes the bowel to become “irritated,” or overly sensitive to stimuli. Symptoms

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**Request for
Contact**



Do you know anyone who has been diagnosed with EMS and then attempted pregnancy?

My questions are...

1. Has anyone been pregnant during EMS?
2. If so, what medications if any did they take?
3. Were there any side effects from medications to mom or baby?
4. How did the disease react (worsen or better) to pregnancy during and after?
5. Are there any children born from a mother with EMS?

I would like any information that even pertains to medications and pregnancy.

I also would like to know if anyone could recommend a doctor that treats EMS close to my area? My current doctor is on leave, and not sure when he'll be back. He practices in Chattanooga, TN. I live in Trenton, Georgia. (35 min from Chattanooga, 2 hrs from Nashville, TN, Birmingham, AL, and Atlanta, GA going in all directions)

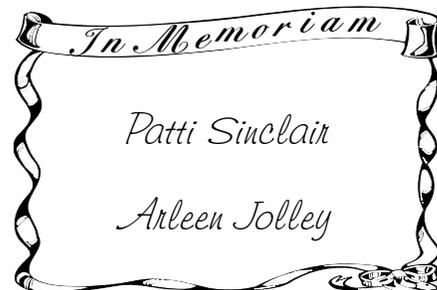
Thank you for your time.

Diane Holmes

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**Join our new
e-mail list**

"The NEMSN Connection"

This is a private email service provided by NEMSN to communicate personally with other members via email. To be placed on our Connections list, please write to NEMSN2005@aol.com typing NEMSN Connection on the subject line. You may use your first name, first and last name both, or you may use a pseudonym for your ID. It doesn't matter which name you use. List up to four personal interests and include your valid e-mail address.

Please JOIN and get connected.

NEMSN2005@aol.com

Mission Statement

The National Eosinophilia-Myalgia Syndrome Network, Inc., is a non-profit organization dedicated to helping EMS survivors and their families by offering educational information and peer support. NEMSN is also committed to encouraging research to improve treatment for L-tryptophan-induced EMS and to increasing awareness of the cause and effects of the dis-

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The NEMSN does not engage in the practice of medicine or law & does not claim to have legal or medical knowledge. All persons should seek the advice of their own lawyers & medical professionals. Opinions expressed by individual writers herein are those of the writers & not necessarily those of the NEMSN Board of Directors or its committee or sub-committee heads, nor of the Editor. Information is intended merely to inform readers. Drugs & treatments & legal issues should be discussed with readers' own physicians & attorneys.

Irritable Bowel Syndrome *Continued from page 1*

may occur even in response to normal events, such as eating a meal.

Upper gastrointestinal symptoms are commonly reported by IBS patients with 25% to 50% of patients reporting heartburn, nausea, abdominal fullness, and bloating. In addition, a significant number report intermittent upper abdominal discomfort or pain (dyspepsia).

Many IBS patients also report non-gastrointestinal symptoms such as fatigue, muscle pain, sleep disturbances, and sexual dysfunction. Up to 66% of IBS patients report non-gastrointestinal symptoms compared to less than 15% of healthy individuals. These non-gastrointestinal symptoms may be due to IBS coexistence with another disease or condition such as fibromyalgia, chronic fatigue syndrome, and interstitial cystitis. For example, the estimated prevalence of IBS in patients with fibromyalgia (FMS) is 30% or more with similar findings of FMS in patients with irritable bowel syndrome.

Diagnosis of IBS

There are no physical findings or diagnostic tests that confirm the diagnosis of IBS. Therefore, diagnosis of IBS involves identifying certain symptoms consistent with the disorder and excluding other medical conditions that may have a similar clinical presentation.

The first step in making a positive diagnosis of IBS is for a doctor to identify if an individual has the symptoms of IBS. This is best determined by the use of the Rome Criteria, which is a collection of the most common symptoms that typify the disorder. These include abdominal pain or discomfort for several months that is associated with two of the following: 1) the pain or discomfort is relieved by defecation, 2) the pain or discomfort is associated with an increase or decrease in stool frequency, and/or 3) the pain or discomfort is associated with the stools becoming harder or softer in consistency.

The next important step is to exclude signs and symptoms that are suggestive of a condition other than IBS which may present with symptoms similar to those seen in IBS – but with uniquely identifying features – such as inflammatory bowel disease or GI infections. A medical history and physical examination, laboratory, and GI tests can help to exclude these other diagnoses. Typical signs and symptoms the physician will look for include anemia and other

abnormal blood tests, blood in the stool, unexplained weight loss, fever, and family history of inflammatory bowel disease or colon cancer. These signs and symptoms are usually not explained by IBS and can represent other medical problems. When these symptoms occur, they should be brought immediately to the attention of a physician.

Treatment

Patients with mild IBS symptoms comprise the most prevalent group, and are usually treated by primary care practitioners, rather than specialists. They do not see a clinician very often, and usually maintain normal daily activities. Treatment is directed toward education, reassurance, achievement of a healthier lifestyle, and occasional medication. Dietary changes work for some and might include avoiding or reducing offending foods that may trigger symptoms. The influence of diet is unique to each individual and there is no generalized dietary advice that will work for everyone.

Pharmacologic (drug) therapy is best used in IBS patients with moderate to severe symptoms which do not respond to physician counseling and dietary changes. First line treatment has traditionally been aimed at treating the most bothersome symptom because of the lack of effective treatment for the overall improvement of multiple symptoms in IBS patients. However, new therapies for IBS have been recently introduced and have been shown to effectively treat multiple symptoms of IBS in some people.

Other treatments may include hypnosis, relaxation training, and behavioral therapies. These can variously help to reduce pain and to manage symptoms. Complimentary and alternative therapies ranging from the use of probiotics to yoga are also being evaluated for the treatment of IBS.

For individuals with IBS, effective diagnosis and treatment starts with the recognition of the validity of symptom complaints. Working in partnership with a physician or care-provider can help achieve the best possible results. Once a diagnosis is made it is helpful to develop a treatment plan and an outcome goal in an effort to control symptoms. Each individual's symptoms may vary and respond differently to treatment.

Conclusions

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Irritable Bowel Syndrome

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IBS is a common, chronic disorder characterized by flare-ups and remissions, which presents with symptoms of abdominal pain and/or discomfort and altered bowel habits. It has a chronic relapsing course and can overlap with other functional GI (e.g., dyspepsia) and non-GI (e.g., fibromyalgia) disorders.

Doctors diagnose IBS based on identifying symptom criteria and excluding organic disease with minimal diagnostic evaluation. This "positive" diagnosis of IBS (as opposed to a diagnosis of exclusion), if made properly, is rarely associated with other explanations for symptoms. Although there are many expensive and sophisticated tests available for the evaluation of IBS symptoms, these are generally not needed for patients with typical symptoms and no features suggestive of organic diseases.

Future studies will further enhance our understanding of this condition and lead to newer, more effective treatments. The fact that definite structural or biochemical abnormalities for these disorders cannot be detected with conventional diagnostic techniques does not rule out the possibility that neurobiological alterations will eventually be identified to explain fully the symptoms of most functional disorders.

The treatment of IBS is based on a working partnership between you and your doctor. You can help by giving your doctor as much information as possible on your symptoms and how they respond to treatment. The key to achieving relief for IBS is for patients to understand that IBS is a complex motor and sensory disorder. A strong

Meet Your New Secretary

Hello to all NEMSN Members,

My name is Ann Flaherty. I am 64 years old and retired in '05 after 18 years with Lorain County Children Services in Elyria, Ohio. When I left I was the Supervisor of the Clerical Staff. Before that, I worked for many years doing secretarial work in the private sector.



When I told my former Supervisor that I had volunteered to be the recording secretary for your organization, she was amazed. She said it was always like pulling teeth to get me to go to the LCCS Board Meet-

ings to take notes when I needed to fill in for her.

I live in Avon Lake, Ohio and am the mother of a grown son and daughter and am recently widowed. This is the first commitment that I have made to anything since the loss of my husband.

My interest in your organization is Sandy Kintz, your newsletter editor. Sandy is a terrific person and has been a wonderful friend to both me and my husband for many years. It is an honor to make a contribution to you lovely people who have the misfortune of having to deal with this terrible illness. God bless you all.

Ann Flaherty

partnership between a knowledgeable patient and an empathetic, knowledgeable health care provider can produce significant improvement and control over symptoms for most individuals with IBS.

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IFFGD is a nonprofit education and research organization. They offer a wealth of information about IBS and other functional disorders through their publications and web sites. Find out more by going to their web site at www.iffgd.org or www.aboutIBS.org; or call them toll-free at 1-888-964-2001.

Diane's Story

Continued from page 5

other illnesses much more readily. It has other long-term, dangerous side effects as well.

I come from a family of healthy people with life-spans into their 90s. I do have one distant relative who has lupus, but other than that, we are not aware of autoimmune diseases within our family. Like many of you, I want to take responsibility for my health. I'm not willing to settle for the treatment plan which my specialist has outlined for me indefinitely.

I welcome emails. I am willing to provide my telephone number but I don't want to just give it out not knowing who might receive it. Thank you so much.

Diane Roenfeldt

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Diane's Story

by Diane Roenfeldt

To those of you at NEMSN:

I contracted EMS back in the fall of 1988. I was the single mother of two children and in my second year of law school at the University of Oregon. Luckily, I was referred to several very good physicians and I was diagnosed at that time as having Eosinophilic Fasciitis. My specialist told me not to take any more supplements, including L-tryptophan and treated me with Prednisone. I was later able to resume my studies and my parenting responsibilities.

Several years later my mother was reading an article in the Seattle Times about EMS. She sent the article to me in Arizona, where I have been living since 1991. She wondered if what I had experienced was perhaps EMS not EF. I contacted my original specialist along with some other doctors. I also contacted Gayle Troutwine, an attorney in Portland, Oregon, who was handling EMS cases. Everyone, including the physician for Showa Denko, agreed that I had EMS.

During the past 18 years, I've been quite fortunate compared to many of you. My heart goes out to so many of you who have shared your stories.

Most of the time my EMS symptoms have not interfered substantially with my life. I was lucky enough to be in great health prior to contracting EMS so perhaps that helped. I have found ways to help cope with the symptoms.

I definitely noticed the cognitive impairment especially in light of my

work. There are some days when I wonder if people think I'm not very intelligent. Writing things down, making lists, and asking people to remind me of things does help. But there are also those days when I make some (dumb) mistake in my work or forget something important.

Living in a warm (okay, HOT) dry climate seems to help me significantly. I do not tolerate cool temperatures or dampness. Fatigue and stress are the most typical culprits which then lead to a relapse. While doctors may not want to use the word "relapse" when it comes to EMS, I use that term as a shorthand way of describing those periods when the myalgia and fatigue interfere with daily life to the point where I have to take off work, go to bed, and/or cut out all non-essentials.

Last year at my annual check-up my primary care physician told me that my liver enzymes were elevated. I was referred to a specialist and had a liver biopsy in August 2005. I was diagnosed with Autoimmune Hepatitis. In addition to seeing the specialist, I also went to the Mayo Clinic and the Mayo Hospital (Liver Transplant Clinic) here in Scottsdale for a second opinion. I was also diagnosed with Restless Leg Syndrome (RLS) after going to a sleep study clinic.

I started doing more reading on autoimmune diseases and more study on EMS and AIH (the abbreviation for Autoimmune Hepatitis). I had not known that once a person develops one autoimmune disease, he/she is more susceptible to developing a second one.

Of course some of you may have had the same experience I have had which is that some doctors don't

want to acknowledge EMS as being an autoimmune disorder or an ongoing disease.

The treatment for AIH is typically Prednisone and Imuran (azathioprine, an immunosuppressant medication). Most people with AIH will have to take these drugs for life.

Those of you who have taken Prednisone may know that it has some very powerful qualities. The good effects of Prednisone are responsible for saving lives in many cases of many kinds of disease. The negative side effects of Prednisone, especially for those of us taking it over a long period of time, are definitely cause for concern.

Now that I have developed AIH along with the earlier EMS, I have been forced to significantly modify my lifestyle and change jobs. AIH causes fatigue – just like EMS does. I have also noticed that I am having more problems with cognitive impairment even though I am only in my late forties (too young for dementia or senility).

I am wondering if there are any other people with EMS who have now also developed AIH. If so, I would be interested in hearing from you. I would also be interested in having my liver specialist speak with any of your health care providers especially since liver specialists usually don't know much about EMS.

I am also interested to hear from anyone who would like to share alternative treatment success stories. I really do not want to continue taking Prednisone. It lowers your immune system thereby causing you to become ill with

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Reactions to Cipro, Levaquin, and Other Fluoroquinolone Antibiotics

Jay S. Cohen, M.D.

Since the December, 2001, publication of my article in the *Annals of Pharmacotherapy*,¹ I've received hundreds of e-mails from people suffering from devastating, long-lasting side effects associated with Cipro, Levaquin, Floxin, and other fluoroquinolone antibiotics. Most of these people are young and had been healthy and active.

These antibiotics have legitimate uses in treating infectious diseases, but they are overused for minor conditions such as sinusitis, prostatitis, and bladder infections. My stance is that Cipro, Levaquin, and similar antibiotics should be used only when other, safer drugs are ineffective, or for organisms that are only sensitive to fluoroquinolones.

As I said on National Public Radio in October 2001, I strongly believe that all people placed on these antibiotics should be warned about infrequent yet serious reactions that may cause joint, muscle, or tendon pain or rupture, nerve pain (burning, electrical sensations, tingling), muscle weakness, thinking or memory problems, heart palpitations, rapid heart rate, gastric problems, skin rash, or many other unusual physical or psychological symptoms. These reactions can occur quickly and suddenly, and patients should alert their doctors immediately.

Doctors, for their part, must recognize that these symptoms can lead to severe, long-term pain or dysfunction, and should stop the antibiotics immediately if at all possible. Because adverse reactions may increase in severity and duration with each exposure, patients with these reactions should not receive fluoroquinolones again. I'd hoped that my article would accomplish this, just as it prompted the U.S. Centers for Disease Control to alter their guidelines for treating anthrax. But it hasn't had the same impact on the medical system.

"These adverse reactions can occur quickly and severely. Doctors must be better informed."

Most people do fine with these antibiotics. For those who don't, the effects can often be minimized with proper warning and prompt response. Unfortunately, few patients were given any warnings. Again, their rights of informed consent are violated.

On the hopeful side, I have spoken to the FDA about this issue. They are taking a very serious look at the problem. But although the FDA has already received thousands of reports, action is slow. And even if the FDA requires new warnings in package inserts and the PDR, most doctors will never notice

them, and because of the unrelenting influence of the drug industry, most doctors will continue to overprescribe these drugs when other, safer, cheaper drugs would do.

So you'd better be informed. Preventing fluoroquinolone reactions is much, much better than trying to treat them, because there is no known, specific treatment. Below is the information that I have sent to people seeking help. I don't know if any of these suggestions is highly effective, but having experienced a severe, long-term disability myself in the mid-1990s and now having improved considerably, I encourage people to keep asking questions and trying things. You can also connect with others enduring similar experiences with fluoroquinolones at the following websites: ***

INFORMATION FOR PEOPLE WITH FLUOROQUINOLONE-RELATED REACTIONS

I have sent this information to hundreds of people who have contacted me about their reactions following the publication of my paper. I wrote the paper so that people having these types of problems might get accurately diagnosed, because most physicians have no idea how severe some of these fluoroquinolone-related reactions can be.

First, I should explain I am not an expert on Cipro, Levaquin, or other fluoroquinolone antibiotics. I am a researcher (I do not see patients), and my major area of expertise is medication reactions, which you can read about in my medical journal articles and my recent book, *Over Dose: The Case Against The Drug Companies* 9 (Tarcher/Putnam, info & reviews at amazon.com). I wrote the article about fluoroquinolones because of the reports I received and because no one was paying attention to this serious problem. My knowledge about fluoroquinolones in particular and antibiotics in general is limited to what is contained in the article. I have not conducted any new research on fluoroquinolones since writing my article in the *Annals of Pharmacotherapy* in December, 2001, so you need to check the medical literature and others sources for updated information.

Regrettably, there are few doctors who are informed about fluoroquinolone-related reactions. You might find information about knowledgeable doctors at some of the fluoroquinolone websites, where people have posted a lot of useful information.

As far as I know, there are no specific treatments for the nerve or tendon/joint/muscle problems associated with Cipro, Floxin, and Levaquin, and other fluoroquinolones. Most of my information is hypothetical or anecdotal; some of these recommendations may help some people, but not others.

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Reactions to Cipro, Levaquin, and Other Fluoroquinolone Antibiotics

(Continued)

by Jay S. Cohen, M.D.

Medications such as amitriptyline or other tricyclics, or Neurontin (gabapentin), may be helpful for neuropathic pain (tingling, burning or electrical sensations) or nerve pain. Muscle spasms, twitching, tremors, and seizures may be helped with long-acting benzodiazepines such as clonazepam (Klonopin) or diazepam (Valium). SSRI antidepressants (Zoloft, Paxil, Effexor, Prozac, etc.) are occasionally helpful for depression. Because patients' nervous systems are sometimes very sensitive, these drugs should be started at very low doses and increased, if necessary, very gradually.

Magnesium (chelated) in doses of 400-1000 mg/day may be useful for reducing neuropathic pain or muscle spasms in some people. Doses over the U.S. recommended daily amount of 320 for women and 400 for men should always be taken with a doctor's supervision. Seniors, people with kidney disorders, and those taking medications for heart, hypertension, or other vascular or neurological disorders should have medical supervision even for RDA doses of magnesium.

Interestingly, another doctor has also been recommending magnesium, as low doses of milk of magnesia (1 or 2 teaspoons twice-daily), to be taken for several months. The theory is that because of the affinity of minerals for these antibiotics, this might help leech some of the remaining fluoroquinolone molecules from the tissues. Some patients have benefited, but not all. In discussion with this doctor, our sense is that calcium, magnesium, and perhaps other minerals may be beneficial. With magnesium, better absorption is important to get the magnesium into the tissues, so chelated magnesium or a magnesium solution might work best. As with all of these recommendations, there's little solid science, so it's trial and error. (For more information on magnesium, please go to the other magnesium sections of this website.)

B-vitamins have been reported to reduce tingling. One person wrote to me that high doses of lecithin have helped with memory problems. GABA, an amino acid, has some similar qualities to Valium and Klonopin and may be helpful for anxiety, nervousness, or insomnia.

Anti-inflammatory drugs are controversial: some people have written to me that they have helped, especially for muscle/joint/tendon pain; others have written that they have worsened their conditions. If you have benefited from anti-inflammatory drugs, you might obtain additional benefit from high doses of omega-3 oils (fish oils; EPA/DHA). There is considerable literature on this. Omega-3 oils take time to work, but the ultimate result can

be better than standard anti-inflammatory drugs (NSAIDs).

Many alternative doctors are knowledgeable about magnesium, GABA, omega-3 oils and, perhaps, about other possibilities.

Corticosteroids (cortisone, etc.) are very controversial. Doctors sometimes prescribe steroids in the hope of reducing the reactions, but many people have written that steroids actually made their cases worse. Steroids should be used with great caution unless there is a specific indication.

Fluoroquinolone-linked reactions can be nasty, and recovery varies from individual to individual, with some reactions resolving quickly and others lasting years. That's why I do not advocate using fluoroquinolones as the first antibiotics for treating minor infections. If we are ever to change the medical-pharmaceutical mindset about this, it will be accomplished by patients. So please submit a Medwatch report. It's easy to do at: www.fda.gov/medwatch/report/consumer/consumer.htm. Or call 800-FDA-1088).

I regret that I cannot give you a more specific, well-proven remedy for these reactions. It is tragic -- and very frustrating -- that the medical-pharmaceutical system frequently fails to recognize these problems and, therefore, doesn't warn patients or doctors. So doctors not only fail to recognize the reactions, but continue to prescribe fluoroquinolones to people who've already shown signs of toxicity previously. It's a terrible situation, but not unlike I've seen and written about with other drugs. I hope that your condition resolves soon. Sincerely, Jay S. Cohen, M.D.

1. Cohen, JS. Peripheral Neuropathy with Fluoroquinolone Antibiotics. *Annals of Pharmacotherapy*, Dec. 2001;35 (12):1540-47.

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