

The Fibromyalgia Connection

The Fibromyalgia Association of Houston, Inc.

Autumn 2001

Volume 8 Number 3

Special Saturday Conference

The Fibromyalgia Association of Houston (FMAH) is proud to announce that it will be hosting a very special patient conference on **Saturday, September 22, 2001**. This conference will replace our regular meeting that would normally be held on the fourth Tuesday of the month. The director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) of the National Institutes of Health, **Stephen Katz, M.D., Ph.D.**, will be a featured speaker. His topic will be "Research on Fibromyalgia: Progress and Promise." Dr. Katz's department is charged with reviewing grant applications and deciding which research projects merit funding. Come learn how your tax dollars are being spent to find a cure for fibromyalgia.

Also speaking that day will be our own FMAH medical director, **Richard Rubin, M.D.** He will discuss treatment of FM, including how to evaluate alternative treatments. If you apply his "Rubin's Rules" for selecting alternative treatments, you will have a better chance of making a good choice among a number of bewildering options.

Anesthesiologist **Richard Patt, M.D.**, president and chief medical officer of the Patt Center for Cancer Pain & Wellness, will be our final speaker. He will be discussing "Drug Therapy for Chronic Pain." Dr. Patt has years of experience with pain medicines and is an

expert in helping patients with severe, chronic pain. Dr. Patt spoke about pain relief at a regular meeting last year and was very informative.

The conference will be held at **St. Bernadette Catholic Church, 15500 El Camino Real, in Clear Lake**. Take I-45 South to El Dorado Blvd and go east (left). The church is about 2 miles on the left, at the corner of El Dorado and El Camino Real. Look for the signs directing you to the Family Life Center. The doors will open at 8:00 a.m., and the first speaker will begin at 9:00. The conference will end at 1:00 p.m. We will serve a light snack at 11:00 a.m. You will also have an opportunity to visit with the vendors who will have information about their products and services available at their booths. Be sure to register for some exciting door prizes!

The conference is **FREE** and open to everyone. However, we do need to know how much food to prepare, so **please make a reservation** to attend. Just call our Hotline at 713-664-0180 and leave your name (please spell it), your phone number, and how many will be attending. You may also email the same information to FMAHouston@yahoo.com. **Please make your reservations before September 19, 2001**. We will have limited seating, so please make your reservations early.

Remember, reservations are free but required!

2001 Meeting Calendar

Support group meetings will be held on the fourth Tuesday of each month from January through October. The November/December meeting will be the first Tuesday of December. We greatly appreciate that the Westbury Baptist Church provides space for our meetings, but FMAH is not affiliated with any church.

Companions are welcome. Please feel free to bring a chair cushion so that you will be comfortable. If you wish, you may bring a snack and something to drink. All meetings are free and open to the public. FMAH reserves the right to substitute alternative speakers if necessary, so for more current information, please call (713) 664-0180.

Location: **Westbury Baptist Church, 10425 Hillcroft**
(Just north of Willowbend — see map.) Look for signs at the Family Life Center, toward the back of the building.

Time: **6:30 p.m.** New members, please come 15 minutes early to register.

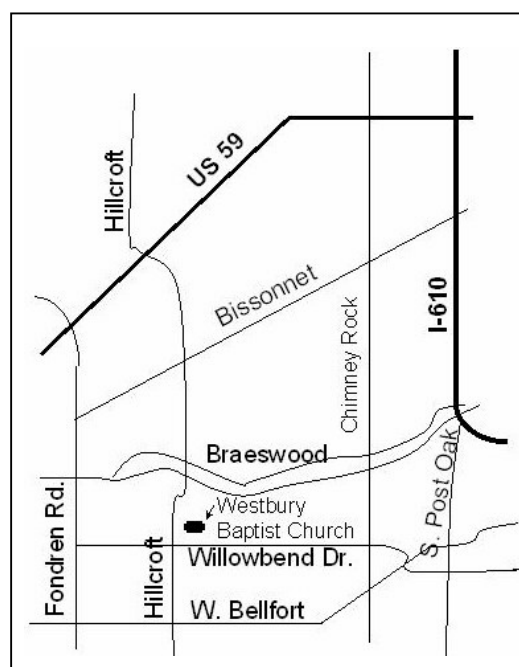
August 28, 2001 David Berg, M.S., Director of Hemex Laboratories

September 22, 2001 Special Saturday Conference
NOTE: There will not be a Tuesday meeting in September.

October 23, 2001 Patricia Salvato, M.D.
“Chronic Fatigue and FM”

Thanksgiving: No November Meeting

December 4, 2001 Special Date! White Elephant Gift Exchange



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Meeting Schedule

August: Do We Have a Clotting Defect?

The Laboratory Director of Hemex Laboratories, **David Berg, M.S.**, will speak to us on August 28, 2001, at our regular meeting. Hemex Laboratories, located in Phoenix, Arizona, is a leader in research to determine if fibromyalgia is caused by a blood clotting defect. *"To Clot or Not to Clot, That Is the Question – Fibromyalgia Equals a Clotting Defect"* is the title of Mr. Berg's talk. His theory is that FM may be due to a problem with blood clotting and that treating it with a blood thinning medication (heparin) would relieve symptoms. Come join us for a thought-provoking evening, 6:30 p.m. in our usual room at Westbury Baptist Church.

September: Special Patient Conference!

Please see page 1 of this newsletter for details. Remember to make your reservations **NOW** by calling the Hotline at 713-664-0180 and leaving your name (spell it, please!), phone number, and number of people attending. You may also email your information to FMAHouston@yahoo.com.

This conference takes the place of our regular September meeting. We look forward to seeing you on Saturday, September 22, 2001, at 8:30 a.m.

October: Chronic Fatigue and Fibromyalgia

Are chronic fatigue syndrome and fibromyalgia the same disease? How are they different? Are there effective treatments for both? FMAH is

pleased to present chronic fatigue specialist **Patricia Salvato, M.D.**, as our speaker for October. Come join us on Tuesday, October 23, 2001, at 6:30 p.m. for a very interesting evening. We're expecting a large crowd to hear Dr. Salvato, so come early for a good seat. We'll meet in our normal meeting room in the Family Life Center. Signs directing you to the meeting will be posted around the building entrances.

November: No Meeting

Due to the Thanksgiving holidays, we will not have a meeting in November. Have a happy and blessed Thanksgiving!

December: White Elephant Gift Exchange

Let's have some fun! We will have a Holiday Gift Exchange and refreshment party on a special day, **Tuesday, December 4, 2001**. Please bring a wrapped "white elephant" gift to be exchanged. It's fun to see what others get and then plot how to take it away from them. You may not end up with your first choice, but you will have lots of laughs. This gift may be something that you already have in the house, or find at a garage sale. It should be worth less than \$10. FMAH will provide the drinks. If you can bring a dessert or cookies, we'd appreciate it. Note the unusual date: Tuesday, December 4, 6:30 p.m.

Videotapes of most speakers are available at the meetings and by mail. The most popular are shown on the order form on page 11. Others are available by request.

FAME 2001

Mary Harper and Aaron Hamilton attended FAME 2001 in Chicago, June 22-24. The conference, sponsored by the National Fibromyalgia Awareness Campaign, featured a half-day session for support group leaders, a one-day seminar for medical professionals, and a full-day patient assembly. The conference focused on current fibromyalgia research and offered hope and promise for FM sufferers.

Dr. Dennis Turk, from the Department of Anesthesiology for the University of Washington, spoke of the evolution of the diagnosis of fibromyalgia. Currently one of the diagnosis criteria for fibromyalgia is for a patient to have 11 of 18 tender points. Dr. Turk feels that a patient should rate the sensitivity of a tender point on a scale of 1-10 rather than simply giving a yes/no response. The ratings would then be totaled, and this would set a new standard to diagnose FM. A study he conducted among his patients showed that those with a total rating over 25 did have FM although not all of them had at least 11 tender points. A patient with fewer, yet more severe, tender points is just as likely to have FM as a patient with all 18 tender points. This rating system could also aid in monitoring a patient's treatment program. Tracking the ratings over time could show which treatments are more effective for a particular patient. Dr. Turk also emphasized that the components of the diagnosing exam should be standardized. These include a patient's body position during the tender-point exam (i.e., sitting or standing); the order in which the tender points are tested; and assuring that a physician uses a thumb, rather than a finger, to apply pressure.

Dr. Denise Park, from the University of Michigan's Department of Psychology, shared findings of a study on the cognitive function of fibromyalgia sufferers. Patients were matched

with a healthy person of the same age as well as a healthy person 20 years older, all with the same educational background. They were given math and vocabulary exams and assessments to test their short- and long-term memory. As suspected, the fibromyalgia patients suffered from poorer short-term and long-term memory than their counterpart of the same age as well as the person 20 years older. The study surprisingly found that while FM patients had equally competent math skills as their same-age group, they showed a deficiency in their vocabulary skills. The researchers have not been able to explain the reason FM sufferers would be lacking in verbal skills. The team hopes to advance this study with the use of brain scans. Current brain scan studies show that older people use more of their brains to think through processes than a younger person uses. The researchers would like to focus on FM patients to see how their brains are working during thought processes.

Alternative treatments have gained popularity in the FM community. Dr. Tony Lu of the Loyola University Health Systems informed the group of the effectiveness of these treatments. Hypnosis was the highest rated for both its long-term value and its symptom relief. Acupuncture was given a medium rating because, although patients feel it is immediately beneficial, the relief gradually fades and the acupuncture must be repeated. Massage received the lowest rating because of its short-term benefits. Of course it feels great at the time, but within a day or two, all symptoms are usually active again.

Since they are among the greatest challenges for FM patients, sleep abnormalities were discussed in great detail. Dr. Howard Kravitz, from Rush Institute of Mental Well-Being,

gave an overview of what the body goes through during sleep. Level 4 is the restorative stage of sleep, yet we spend only 13% of our night in this stage. It is this stage that FM sufferers generally have trouble reaching, and that is why we wake up feeling fatigued. While antidepressants can sometimes be beneficial sleep aids, medication in general has not proven to be very effective.

Promoting better sleep is something we must do for ourselves. Dr. Kravitz recommends regular sleep hours, going to bed at the same time every night, and waking up at the same time every morning. He also suggests avoiding caffeine, nicotine, alcohol, and eating a large meal prior to bed. Using the bed only for sleeping and allowing yourself a relaxation time prior to bed are also beneficial. The most common things that disrupt our sleep are noisy surroundings, having the bedroom too hot, and the chronic use of hypnotics. While exercise is strongly encouraged for FM sufferers, it should be avoided three to four hours before bedtime.

Texas's own I. Jon Russell, M.D., Ph.D., offered hope for the FM community when he shared a formula that could ultimately lead to a blood or urine test for fibromyalgia. So far the formula has proven to be 90% effective during the experimental phase. A blood test for FM would lead to greater physician acceptance and more support from insurance companies. A test would prove that a patient does in fact have the disease, and the diagnoses would be more widely accepted.

Steve Fanto, M.D., from Absolute Rehabilitation and Sports Medicine presented a lengthy list of medications used to treat FM. While no single drug helps all people, the encouraging point of his presentation was that there are a lot of options available. Just because one thing does not work, do not give up. Other alternatives are available. The Rehabilitation Institute of Chicago's Dr. R. Norman Harden,

could not emphasize strongly enough that improved aerobic capacity will decrease pain. Start slow, but do try to get some form of aerobic activity every day. People often shy away from exercise because they already hurt and they believe they have to do something complicated like step aerobics or jogging. Just make an effort to walk to your mailbox, and then when you are comfortable doing that, walk to your neighbor's house, then walk past two neighbors' homes, and so on.

Sabrina Johnson, Founder and CEO of FACES (Fibromyalgia Association Created for Education and Self-help), a Chicago-based support group, shared some important tidbits with us. It is important to remember that FM is a family affair. Even though you may be the one with the disease, your family members are hurting as well. Consider their feelings. We often think that they don't understand, but they may understand more than we realize. She also encourages patients to fight for their Social Security benefits or other disability services, even if they don't think the service they will receive is very substantial. Once one service recognizes someone as being disabled, other services will follow suit and may open doors to prescription aid, transportation services, housing benefits, and other important services.

A great deal of information was presented during the three-day seminar, which was very positive for the future of FM. Physicians and medical researchers are learning more each day and getting farther along in the journey for a cure. While having dinner with Andrew Holman, M.D. from Valley Orthopedics Associates in Washington, we asked if he thought there would soon be a cure. He said, "I don't think there will be a cure, I **know** there will be a cure, and we are **so** close!"

Finding Information on the Internet

Lisa Lorden is somewhat of a celebrity in the chronic fatigue and fibromyalgia community. For the past three years she has been the guide for the About.com CFS/FM Web site. She did a presentation at the FAME 2001 conference about how to find FM information on the Internet. The Internet has gained popularity because of its speed, timeliness, and the amount of information available. Gaining access to information is easy to do through a search engine such as Yahoo or Google. There is a lot of information available that you can search with specific keywords, yet there are no quality standards and it's common to find sites that are out of date.

You can also get information by going to a specific Web site that you are already familiar with, see advertised, or read about (as in our newsletter). This generally leads you to more specific information on a topic, and most sites provide you with links to other related sites.

Lisa emphasized that once you find the information you are looking for, you need to evaluate if you can trust it. Anyone can claim to be a medical expert on the Internet, so beware. Many Web sites appear to be informational, yet are actually trying to sell a product. Evaluate the site's motivation; if it's sales related, it is likely to be biased. It is best to check credentials of the author or sponsor of the site and make sure the information is based on a reliable source.

A reliable site will present various perspectives rather than claiming to have all the answers. Question Web sites that claim to be the best or that disrespect other sites. Watch closely for outdated information. Look for a date on the site, as old information may no longer be accurate. Lisa also reminded us that patients with incurable diseases are easy prey for people

with hidden agendas, so if a site claims to have the cure, it is a sure sign of a hoax. Lisa's favorite sites are listed below:

About.com CFS & fibromyalgia:
www.chronicfatigue.about.com

Co-cure List and Web site: www.co-cure.org

Fibrom-L Community: www.fibrom-l.org

Oregon Fibromyalgia Foundation:
www.myalgia.com

Devin Starlanyl's FM/MPS:
www.sover.net/~devstar

Melissa Kaplan's CFIDS/FMS:
www.sonic.net/~melissk/cfsinfo.html

The CFIDS Association of America:
www.cfids.org

Lisa Lorden has just accepted a position with the National Fibromyalgia Awareness Campaign to start their Web site and edit their upcoming magazine. Even though she has left About.com, someone else will be taking over her Web site. Please check out the site (chronicfatigue.about.com) to see all of Lisa's valuable information, and watch for more updates to come when someone new fills her role. The site contains a wide variety of articles, with topics from coping strategies to advocacy, medications to Social Security. You will even find personal stories, humor links, and interesting facts. The site has a newsletter you can subscribe to, and chat rooms if you like talking to other FM sufferers. It is a valuable site, and Lisa has done a wonderful job of supplying us with information over the past three years. We wish her well in her new position!

Extra! Extra! Read All About It!

FMAH has two new books available to purchase. The books are *Fibromyalgia and the Mind Body Spirit Connection*, by William B. Salt II, M.D., and Edwin H. Season, M.D., and *Irritable Bowel Syndrome and the Mind-Body Brain-Gut Connection*, by William B. Salt II, M.D. The books sell for \$23.00 each, including shipping.

Fibromyalgia and the Mind Body Spirit Connection looks beyond traditional medication and is truly a **self-help** book. This book focuses on teaching a patient how to stop treating just the body and incorporate the mind and spirit into his or her treatment program. The book walks through seven steps for achieving a more healthy lifestyle by educating yourself about FM, promoting self-care, managing your illness, and taking action. It explains the roles that sleep, diet, supplements, and exercise play in your treatment and takes you through the process of working with your doctor to get the proper medicinal treatment. The book is straightforward and easy to understand. It is perfect for someone who is newly diagnosed or anyone who is ready to take control and play an active part in his or her health care management. Purchase your copy now and start your journey toward making “the connection”.

Irritable Bowel Syndrome and the Mind-Body Brain-Gut Connection follows the same format. It is an excellent resource for the many FM patients who suffer from IBS. The book guides you through an eight-step process to healthier living, and includes wonderful humor for such a delicate problem. This book is also a good resource for those with Crohn’s disease, ulcerative colitis, and other inflammatory bowel diseases.

The Best Medicine

We’ve all heard that laughter is the best medicine, so let’s find some humor in spite of our pain.

You know you have fibro fog when getting lucky means you found your car in the parking lot.

You know you have fibromyalgia when you're sitting in a rocker and you can't get it started.

You know you have fibromyalgia when you know how to spell *rheumatologist*, *gastroenterologist*, *chiropractor*, etc.

You know you have fibro fog when you put both contact lenses in the same eye.

You know you have fibromyalgia when one of the throw pillows on your bed is a hot-water bottle.

You know you have fibromyalgia when everything that works hurts, and what doesn't hurt doesn't work.

You know you have fibro fog when you reach the toilet but forget what you wanted to do.

You know you have fibro fog when you can't finish a conversation because you don't remember what you were talking about.

You know you have fibro fog when you don't call people back because you're not sure they called.

These jokes were adapted from a list found on the Humor Links of the About.com CFS/FM Web site with the permission of Bill Jackson.

To All Our Members

FMAH has never sold, shared, or rented our mailing list, nor will we. You may be assured that your personal information is kept confidential, and that we respect your right to privacy. We are deeply grateful for your donations, and pledge to spend the money in a responsible, thrifty manner.

Important Notice

We would like to remind you that the Fibromyalgia Association of Houston, Inc. is in no way affiliated with any other organization or any for-profit company. Please remember that we are a support and information group only. We are not doctors, and we do not offer medical advice. Our authors express their own opinions, which do not necessarily reflect the opinions of FMAH, its officers, directors, or members. We do not endorse any specific form of treatment, exercise or product or any person.

Credit Cards Accepted

We are pleased to announce that FMAH now accepts both MasterCard and Visa. You may pay for items at our meeting with either credit card, make a donation, or use them for mail orders. Remember that all donations are tax-deductible, and we will be happy to give you a tax receipt upon request.

Got a Computer?

If you have access to a computer and the Internet, you can find FMAH on the Web. For the latest information, check our Web site at www.fmah.org. Be sure to check often, as our volunteer Webmaster Norman Farrington, frequently posts late-breaking "news that you can use." You may also email us from the site, or go directly to our email address at FMAHHouston@yahoo.com.

FAME 2002

Postponed

The Fibromyalgia Awareness Main Event Conference, originally scheduled for April, 2002, has been postponed. We are unsure of a new date, as we want to make certain that our conference does not conflict with other meetings, such as the fall American College of Rheumatology meeting. As soon as we have a new date and more information, we'll let you know. FMAH is committed to having an excellent conference, with top speakers from around the country. It takes a lot of time and effort to organize such an event, and we'll need a lot of help from our members. Thanks for your patience.

Disability Assistance

Social Security disability attorney Robert Hardy has announced that, in honor of out-going president Toby Robbins, he will discount his fee by 20%. When you make an appointment with Mr. Hardy, just mention Toby's name and he will give you the discount. This offer has no expiration date. You may reach Mr. Hardy at 713-529-8888.

Antibiotic Warning

Warning: A class of antibiotics called quinolones, which include Levaquin, Cipro, and Floxin, may be especially hazardous to FM patients. According to Levaquin's own Web site, "ruptures of shoulder, hand, or Achilles tendons have been reported in patients receiving quinolones, including Levaquin. If you develop pain, swelling, or rupture of a tendon you should stop taking Levaquin and contact your healthcare professional." If you are prescribed one of these antibiotics, be sure to ask your doctor if this medicine is right for you.

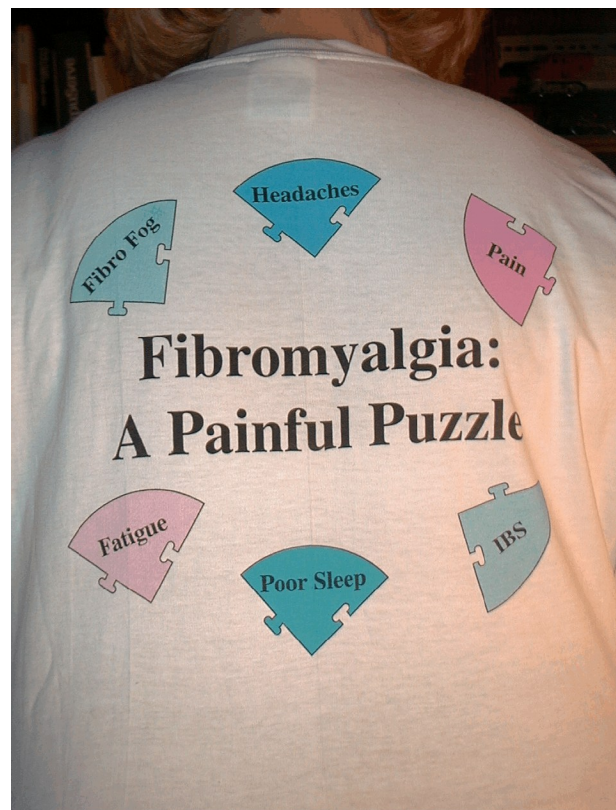
FMAH T-Shirts Are Here!

Are you tired of trying to explain fibromyalgia? Would you like a great way to support FMAH *and* tell people about this frustrating illness? Wear one of our T-shirts!

Designed by our president, Mary Harper, and treasurer Deanne Brown's daughter Christy, the shirt features our "puzzle" logo on the front. The logo is also on the front of our brochures that we send out in the information packets. It says "Piecing Together a World With Hope" and shows a circular puzzle with four pieces labeled "RESEARCH," "EDUCATION," "SUPPORT," and "VISION," respectively.

The back of the shirt reads "Fibromyalgia: A Painful Puzzle" and shows six puzzle pieces labeled with the various symptoms of FM. Now people will better understand your illness when they read the pieces labeled "FATIGUE," "IBS," "PAIN," "HEADACHES," "FIBRO FOG," and "POOR SLEEP," respectively.

The shirts are made out of quality 100% heavyweight cotton and are sized from medium through 4X. They don't shrink, and they wash beautifully. They are available at our meetings or by mail. For only \$10, you can support FMAH and have a great way to raise awareness of fibromyalgia. See the order form on the back page for details.



The following generous donors are people who have given donations by check. We are unable to thank each of you who have given us cash, but we are grateful for all donations. The * indicates donations of \$50 or more.

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FMAH gratefully accepts donations in memory or in honor of a loved one. Please remember us for birthdays, anniversaries, or other special occasions. We will send a card to the honoree advising him or her of your donation. Thank you for thinking of us.

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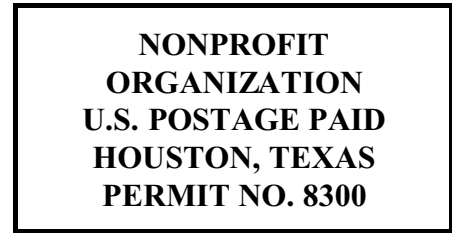
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Change Service Requested

Autumn 2001

Fibromyalgia Syndrome is ...

a chronic condition causing widespread pain and stiffness in the muscles and connective tissues throughout the body. Fatigue is often present and can be severe. Most people will have nonrestorative sleep, awakening in the morning feeling unrefreshed. Other conditions occurring with more frequency in fibromyalgia include headaches, irritable bowel and bladder syndromes, feelings of numbness and tingling, chest pain that's not cardiac related, cognitive and memory problems, and difficulty with anxiety or depression. Treatment includes education, medications, exercise, and lifestyle changes. Over 2% of the population, or 3½ to 5 million Americans, have fibromyalgia; many have not been diagnosed. The cause and cure of fibromyalgia remain unknown.

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