

## Mary's Message

Sometimes, at meetings, I'm asked how I can function so well. After all, I look pretty healthy. Most FM patients look healthy, which makes diagnosing us even harder. When I'm leading the meetings, I try to project a positive manner.

What you don't see is afterwards, when I'm at home and exhausted. Sometimes it takes a lot of energy to get "up" for public speaking, not to mention the work that I do to get everything ready for the meeting.

But I'm not complaining, and I'm lucky I have a relatively mild form of Fibromyalgia. Volunteering my time works wonders to help me forget my pain and fatigue. If I'm on the phone concentrating on someone else's problems or making plans for an upcoming meeting, I'm not thinking about my body.

Distraction is key. Dwelling on your pain only makes it worse. When a person has an illness or discomfort, it's so easy to turn inward and begin a downward spiral into depression and fear.

You can get caught in the trap of thinking only about your body and how everything hurts and will never get better. When that happens, please reach out to someone who will listen.

You can always call the FMAH Information Line at 713-664-0180. We have trained volunteers who will be happy to assist.

Another thing to consider is seeing a counselor who is trained in cognitive-behavioral therapy. Numerous studies have shown that this type of counseling is very effective for FM.

It is very important to me to walk every day. I feel so much better when I move. I started out very slowly, walking for only about five minutes a day. Now I'm up to a half-hour every day!

You don't have to do it all at one time. You can do five minutes in the morning for one week, and then add five more minutes in the afternoon the next week. Everybody has time to start moving. If you don't make the time to move, then you'll

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## Board of Directors Changes

*Mary Harper, President*

I am pleased to announce that Sheshe Giddens has accepted the position of vice president of patient education on the FMAH board of directors. She is a graduate of the University of Texas at Austin with a bachelor's degree in English and Ethnic Studies/African and Afro American Studies. She received a Technical Communications/Desktop Publishing certificate from Houston Community College. She currently works as publications coordinator at The Methodist Hospital. Sheshe is a member of Toastmasters International and serves as FMAH newsletter editor and graphic designer as well as the organization's Webmaster.

We still have a vacancy for the vice president of volunteers position. As announced in the last newsletter, Janet Gingell has resigned to pursue other interests. If you enjoy talking on the phone, this position is for you. We need someone to organize our volunteers, and especially to recruit people to help with various projects. Sometimes, it's just a matter of calling to remind

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*the*  
**FIBROMYALGIA Connection**

The *Fibromyalgia Connection* is published three times a year by The Fibromyalgia Association of Houston, Inc. (FMAH), a 501(c)(3) charity, and its volunteers.

Materials and opinions presented in the newsletter are for information only and do not necessarily reflect the views of FMAH, its officers, directors, or medical advisory board. Fibromyalgia (FM) patients should consult their physicians or other health care professionals for diagnosis and prior to initiating any form of treatment or exercise.

The *Fibromyalgia Connection* is not responsible for typographical errors or omissions in its printed matter. FMAH and *The Fibromyalgia Connection* are not affiliated with any other Fibromyalgia organization.

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Send correspondence to The Fibromyalgia Association of Houston, Inc., P.O. Box 2174, Bellaire, TX 77402, or FMAHouston@yahoo.com.

Visit FMAH online at [www.fmah.org](http://www.fmah.org).

For more information about Fibromyalgia, call the FMAH Information Line at 713-664-0180. A volunteer will return your call.

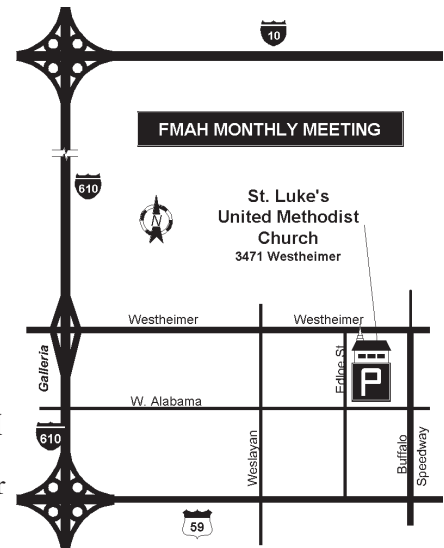
# Support Group Meeting Schedule

We meet at St. Luke's United Methodist Church and greatly appreciate the space they provide for our meetings; however, FMAH is not affiliated with any church.

Companions are always welcome.

All meetings are free and open to the public. FMAH reserves the right to substitute speakers if necessary, so for more current information, please call the FMAH Information Line, 713-664-0180, or visit us online at [www.fmah.org](http://www.fmah.org).

Parking is free in the church lot.



<b>LOCATION:</b>	St. Luke's United Methodist Church 3471 Westheimer (just inside the 610 Loop)
<b>ROOM:</b>	Parlor B, on the Westheimer side of the church
<b>TIME:</b>	6:30 p.m. New members, please come 15 minutes early to register.
<b>January 24</b>	<b>Janet Rinehart, Chairman of the Houston Celiac Support Group</b> "Weird Celiac Disease – It Could Be You"
<b>February 28</b>	<b>Mary Jo Rapini, L.P.C.</b> "Loving and Caring for Yourself"
<b>March 28</b>	<b>Matthew Mireles, Ph.D., M.P.H., President and Director of Research, CRG Medical Foundation for Patient Safety</b> "It Can Be Dangerous to Be a Patient!"
<b>April 25</b>	To Be Announced
<b>May 23</b>	To Be Announced

## January: Weird Celiac Disease – It Could Be You

Many Fibromyalgia patients have been diagnosed with irritable bowel syndrome, but could it really be celiac sprue disease? Many patients have been treated for celiac sprue and found that their muscle pains have disappeared. Come learn what celiac is and about treatments for it.

Our speaker will be Janet Rinehart, chairman of the Houston Celiac Support Group. She has been an officer with the national group, Celiac Sprue Association, for many years and has helped many people find their roads to better health.

## February: Loving and Caring for Yourself

This meeting was originally scheduled for September but was canceled due to Hurricane Rita. Warning! Our speaker for February has requested that only adults attend her talk.

A practicing sex therapist, Mary Jo Rapini, L.P.C., will discuss how to love and care for yourself. Living with a chronic illness affects your sexuality, relationships and how you view yourself.

Mary Jo's frankness and sense of humor will keep you laughing as you learn new ways of thinking about yourself. Mary Jo is in private practice, specializing in chronic illness, sexuality and anger resolution.

## March: It Can Be Dangerous to Be a Patient!

Matthew Mireles, Ph.D., M.P.H., president and director of research at CRG Medical Foundation for Patient Safety, will be our speaker.

Patient safety has become a major concern in the United States. We expect to be treated and healed when we are sick and injured, yet thousands of American patients die every year in our hospitals and clinics because wrong medications are given, wrong medical procedures are performed, and even wrong patients are treated.

There are many ways patients and their families can improve their safety and quality of care. Dr. Mireles will present a general overview of patient safety in the United States and an introduction to the foundation and its research and educational activities. He also will discuss simple ideas and tools to improve your safety as a patient.

He will conclude his presentation with short briefing about

his study in the diagnosis of FM based on hand functionality.

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### "BOARD" CONTINUED FROM PAGE 1

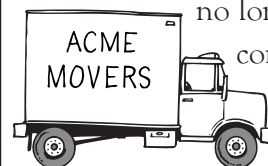
folks of an advisory council meeting. The time involved will vary, but it's not a job that needs to be done every day.

We are also beginning our search for someone to replace Susan Edwards, our current treasurer. Susan has many things on her plate now and would like someone to take over her responsibilities. If you have any accounting or bookkeeping experience, please call us! We'll be glad to tell you more about the position.

Being on the board of directors is a responsibility, but it can be a lot of fun and quite rewarding. The board meets four times a year, and we usually go out to dinner afterward. If you would like more information, please call the FMAH Information Line at 713-664-0180 and leave me a message, or you may e-mail us at [FMAHouston@yahoo.com](mailto:FMAHouston@yahoo.com). We need your ideas and enthusiasm, so please consider joining us.

## If You Move

Please be sure to let us know your new address if you have moved or are planning to move. Each time a newsletter is returned, the post offices charges us \$0.70, which can be a big hit if we fail to stay on top of current addresses. Likewise, if you no longer wish to receive this publication, please



contact us. You can call the FMAH Information Line at 713-664-0180 or e-mail us at [FMAHouston@yahoo.com](mailto:FMAHouston@yahoo.com).

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# *On the Fringes:*

## Men and Fibromyalgia



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*By Sheshe Giddens*

Although Fibromyalgia falls into a category of diseases and syndromes that disproportionately affect women, Fibromyalgia isn't a woman's disease.

One in eight FM patients are male. This number may not be a true reflection of how prevalent FM is in the male population because of the very nature of the syndrome. FM often goes undiagnosed for long periods of time, and some sufferers do not receive a proper diagnosis at all. This, coupled with the fact that men are less likely to seek medical help, means that it is possible that there are far more men with FM than reported.

Although not all men have difficulty getting the proper referral and diagnosis because they are men, the perception that Fibromyalgia is a disease that primarily afflicts women may also hinder men from receiving a proper diagnosis.

"It took 15 years, 12 doctors, and hearing over and over that there was nothing wrong with me. Two doctors said that if I were a woman, they would say it was FM. This was before a doctor actually diagnosed me with it officially," says Michael Alsup., who began to experience FM symptoms in his early 20s.

Alsup also suffers from other illnesses including chronic

fatigue, irritable bowel syndrome, Raynaud's phenomenon, chronic insomnia, and a recurrent seizure disorder.

After getting diagnosed, accepting it as well as coping with it is the same for men as it is for women, but societal pressures and expectations of men present unique challenges. Even in the 21st century, men are judged by their ability to provide financially for their families.

Society's masculine ideal continues to expect men to be physically active and hardworking. FM threatens all patients' abilities to live up to these expectations, but its impact can be more difficult for men to cope with. Fibromyal-

gia can be debilitating, which can affect a person's ability to work.

"Since the three accepted stereotypes for men are that they are athletes, intellectuals, or artists, I'm finding it difficult to maintain my self-image when I'm rarely able to participate on any of those points. Either I don't have the energy or I can't get the thought out before it's gone," says Dan Brooks, who began to experience FM-like symptoms as early as seven years old.

As with any chronic illness, relationships are affected especially because of the very nature of FM. Fatigue may cause patients to withdraw and become less physically active. Because there are no definitive laboratory tests to diagnose FM and no apparent physical signs of the disease, family and friends may be skeptical of an FM diagnosis.

"Others are mostly sympathetic, but many do not understand why I cannot work a regular job when I look healthy and can do so much on occasion," says Alsup.

Like other FM sufferers, Alsup has had to deal with people's perceptions of him based on their lack of understanding FM. Alsup says that some people believe that something may be afflicting him but they believed that it is coupled with "a strong leaning toward just plain laziness and wimpiness."

These perceptions, along with a change in lifestyle can have a

detrimental impact on FM sufferers.

"Most of my male friends have dropped by the wayside as I did less and less of the active, macho activity trips and adventures with them. Some members of my family have just given up on me," says Alsup.

"I dread the person who mutters, 'You're no sicker than I am.' Fortunately, that's happened to me only once. I was on my best behavior, and replied, 'I'm so sorry. Is there anything I can do to help?' The stunned look was priceless," says Brooks.

Support is key.

"I have been very fortunate to have a supportive family and group at work. I have encountered some disbelief in the general population. Generally I am able to win them over with a frank discussion of what my day is like. I do feel that I have met some success, because I am still working and not on disability," says Brooks.

### **Tips for Men**

1. Do you need advice from other men? Go online. Here are some online resources for men with Fibromyalgia.

- [menwithfibro.com](http://menwithfibro.com) – It offers resources for men coping with Fibromyalgia. The Web site includes a section with men's stories, a chat room, and a message forum. It also explores sexual issues as it relates to FM.

- [FibroMenSupportGroup](http://FibroMenSupportGroup) – The online support is part of Yahoo! Health support groups. It is a members-only group. To learn more, visit <http://health.groups.yahoo.com/group/FibroMenSupportGroup/>.
- [The Men's Zone](http://www.plaidrabbit.com/fms/menspage.htm) – This site offers information and support for men with FM. Visit <http://www.plaidrabbit.com/fms/menspage.htm>.

2. Go to a support group meeting. Although the number of women at support group meetings outnumber the men, men are most welcome. Women are often happy to see men who can empathize at support group meetings. "In the Fibro community, however, we seem to be treated like gems – the rarest of the rare – a man who understands and sympathizes," says Brooks.

3. You are not alone. Approximately one in eight FM patients is a man. "Find other male FM patients and forge friendships with them. They will be the ones who truly understand and will provide the companionship and friendships to replace those male friends who fade away when you can no longer share their pleasures," says Alsup.

4. See your physician. He or she will be able to provide you with information about FM and your treatment options.

5. Educate yourself on FM.

# ACR Conference Brings Together the Latest Rheumatological Research

By Mary Harper

The American College of Rheumatology and the Association of Rheumatology Health Professionals held the 2005 ACR/ARHP Annual Scientific Meeting in San Diego, Calif., Nov. 13-17, 2005.

FMAH President Mary Harper and FMAH Secretary Gayle Moses attended the conference, which brought together rheumatologists, nurses, other health professionals, and researchers from around the world.

There were sessions covering osteoarthritis, rheumatoid arthritis, lupus and Fibromyalgia. The FM sessions were an hour and a half in duration and featured four to six researchers describing their work. These meetings were held in a large room at the convention center. It was very gratifying to see a room full of interested professionals listening to the research.

At one of the sessions, Lesley Arnold, M.D., presented the results of two studies on a new drug, duloxetine, or Cymbalta. Duloxetine is a new class of antidepressant which works on serotonin and norepinephrine — both chemicals in the brain. They enrolled only women, with or without major depressive disorder (depression). In one group, they

slowly increased the dose over two weeks to 60 mg twice a day. The other group increased the dosage to 60 mg in only three days. Both groups reported a 50 percent reduction in pain and also an improvement in the level of fatigue. More side effects were noted in the group that quickly increased the dosage, with dry mouth and insomnia reported among some of the patients. It was recommended that the dosage be increased slowly to minimize side effects.

Results of research into the genetic components of Fibromyalgia were presented. It was very technical, but basically they have found that FM aggregates strongly in families. There is the possibility that there is a genetic predisposition to pain perception, which is one reason FM patients feel pain more acutely than healthy controls do. One reason that researchers are so interested in genetics is that if patients are missing a certain gene, then a particular medicine might work better for them. Knowing a patient's genotype would eliminate much trial and error with medicine. The doctor could more confidently prescribe a drug that is more likely to work for that particular patient.

Believe it or not, the research-

ers are still trying to figure out how to diagnose Fibromyalgia. Although the ACR in 1990 defined FM as 11 out of 18 tender points and chronic widespread pain, there is now discussion that the ACR criteria are really useful only for research purposes. One group of scientists believes that having patients complete special survey questionnaires is as diagnostic as the tender-point exam. Since many doctors don't know how to do a tender-point exam, it would make diagnosing FM much easier if patients simply answered questions on a questionnaire.

Because only a relatively few studies could be presented to an audience, the majority of studies were presented in poster sessions. Researchers make up posters detailing their work and the posters are on view for one day. One poster discussed the "Interface between Fibromyalgia and Attention Deficit/Hyperactivity Disorder." Researchers Robert Katz, M.D. and Frank Leavitt, M.D., of Rush University Medical Center in Chicago, wanted to learn if adults with FM and attention dysregulation had symptoms of ADHD in childhood. It is known that many adults with FM also have attention problems, which complicates

cognitive functions. These researchers found that 21 out of 50 FM patients in their study (42 percent) have adult ADHD. However, symptoms of ADHD in childhood are not helpful in understanding why adult FM patients have ADHD. The likelihood that ADHD in FM has its onset in childhood is minimal. They conclude that a great many patients with FM may live with adult ADHD without knowing it because of other disabling cognitive symptoms.

An interesting study by Drs. I. Jon Russell, Robert Bennett, and Joel Michalek was done to see if sodium oxybate would be safe and effective to treat FM. Oxybate is currently approved to treat patients with a type of narcolepsy, a sleep disorder. Also known as Xyrem, oxybate in this study appeared to be safe and improved the symptoms of pain, tenderness and insomnia. It seems that the quality of sleep induced by oxybate was responsible for the reduction in pain. Although potentially very exciting, more research still needs to be done before oxybate can be approved for treating FM.

For more information on these studies, please see our Web site at [www.fmah.org](http://www.fmah.org). The abstracts are posted there and you may print them out for future reference.



**Pictured from left to right: Lynne Matallana, founder of *FM Aware* magazine and National Fibromyalgia Association, and author of *The Complete Idiot's Guide to Fibromyalgia*, joined FMAH Secretary Gayle Moses and FMAH President Mary Harper for a photo in San Diego, Calif., at the American College of Rheumatology conference. Lynne is one of the featured speakers for FMAH's patient conference in September 2006.**

## ACR Session Allows Attendees to "Meet the Professor"

*By Gayle Moses*

I was privileged to attend the 2005 American College of Rheumatology Conference in San Diego, Calif.

One of the sessions of interest to those of us with Fibromyalgia was the one featuring Daniel J. Clauw, M.D., professor of medicine, Division of Rheumatology, at University of Michigan Medical Center.

He is also assistant dean for clinical and translational research, director of the Chronic Pain and Fatigue Research Center, and director of the Center for the Advancement of

Clinical Research. And he sees patients, too!

The Meet the Professor session allows physicians to learn, in a smaller setting, about the research and findings of the featured speaker.

Communication is easier between the speaker and the audience, so questions receive fuller answers than in the larger sessions.

Dr. Clauw and others have found that Fibromyalgia, with its seemingly unrelated symptoms such as headaches, temporomandibular joint disorder, irritable

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**“SESSION” CONTINUED FROM PAGE 7**

bowel, irritable bladder, noncardiac chest pain, and memory and cognitive difficulties among others, is a dysfunction of the autonomic nervous system, which controls the automatic functions of the body such as breathing, blood pressure and heart rate.

It seems that the communication between the brain and this part of the central nervous system is disrupted, so that the neurotransmitters that keep the system running smoothly are not available. This results in the pain, fatigue, and digestion problems that plague those of us with FM.

Interestingly enough, Dr. Clauw has found that this dysfunction is the reason for the overlap in symptoms with FM and other systemic syndromes, such as Gulf War illnesses and chronic fatigue, which present with multiple, unexplained symptoms with no organic findings.

Fortunately, this finding is leading to the development and testing of new medications to reconnect the communication between the brain and the autonomic nervous system.

Although no specific medication for FM are ready for use now, the promise is there. For now, this knowledge allows for expanded “borrowing” of medicines now on the market for other conditions.

Dr. Clauw suggests that the best treatment includes patient

education, medications, mild exercise (working up to moderate as tolerated), alternate therapies, and cognitive-behavioral therapy.

Patient education tops his list as he feels that the FM sufferer needs to understand the illness in order to relieve the stress and anxiety of the unknown and become a partner with the doctor in treatment.

Medications begin with low doses of tricyclic antidepressants, such as Elavil or Flexeril, adding others or changing medications as needed.

Alternate therapies include strength training, acupuncture, biofeedback, and hypnotherapy, among others. Although the evidence is modest regarding the effectiveness of the alternate therapies, Dr. Clauw recommends that the patient be encouraged if interested in trying one of these.

He indicated that although any success may be due to the “placebo effect,” it should be applauded and encouraged, as it relates to giving the FM patient a feeling of control, which is sorely lacking in most cases.

Dr. Clauw is a strong advocate of cognitive-behavioral therapy, which is a program designed to teach patients effective ways to reduce symptoms by increasing coping strategies and to change behaviors that may be adding to their symptoms. He has found that this strategy is effective for nearly any chronic illness.

Dr. Clauw indicated that he and others have found problems with the “tender point” criteria to diagnose FM, because, he believes it is not an objective way to measure tenderness and it gives an inappropriate impression that the nature of the problem in FM is in the muscle. It also encourages the assumption that this affects only distressed, unfit females.

He indicated that 11 out of 18 tender points is an arbitrary number. He demonstrated to the doctors present how they could check for tenderness on an exposed part of the body, such as the arm or hand, without causing the patient undue distress.

Interestingly enough, he has found that tenderness upon touch without the existence of pain in those who are not suffering from FM may indicate a chance that FM or one of the other systemic syndromes may develop in the future.

We were eager to bring back information that there was a “magic bullet” on the horizon. Unfortunately, one is not available.

However, we were extremely pleased to find that researchers, including Dr. Clauw, have uncovered more about the action of Fibromyalgia in the body, which in turn is leading to the development of medications to help us.

There are some in drug trials now, but it may be several years

before the drugs become available. Again, patience is advised, but we have more hope for that “magic bullet” than we did a few years ago.

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**“MESSAGE” CONTINUED FROM PAGE 1**

just have to make the time to be sick. I’d rather move than be sick.

Remember, you are not Fibromyalgia. You may have some symptoms of FM, but you are not the disease. You **do** have choices, and what better time than the New Year to begin making healthy choices? Here’s to a happy, *healthy* new year!

Take care,  
Mary Harper  
President

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## A Note from Gayle Moses

I would like to take this opportunity to thank everyone for their prayers, phone calls, cards, and visits during the illness and death of my husband, Mike. He lost his battle with cancer on July 25, 2006. Your support has carried me through some very trying times, and it continues to do so.

A special thanks to those who were able to join us to celebrate his life and see him to his final resting place. Also my appreciation goes to our phone volunteers who took over for me on my scheduled weeks – even before I could think to ask for help. My prayers are with all of you.

Love, Gayle

The FIBROMYALGIA Connection

# Donor’s List

The following generous donors contributed by check. Unfortunately, there is no way to acknowledge those who made cash contributions, but we do appreciate every donation you give us.

Renee Barnhill	Renate Reibel*
Lt. Richard Brown, USMC Ret.	Bernadean Rosenblatt
Rebeca Dobson	Catherine Scott
Susan Edwards	Sherry Spikes
Mary Harper	Mary B. Harrison,* in honor of Mary Harper. For being a caring person and for all you do. Thank you again.
Anne Harris	Inez McMullen,* in honor of her son Jon Payne
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\* Indicates donations of \$50 or more. Thanks to all of you!

## FMAH Patient Conference

Saturday, September 30, 2006  
Hornburger Conference Center  
Holcombe/Main Street, near the Texas Medical Center

### Featuring:

**Robert Wood, M.D.**  
Fibromyalgia Researcher

### Lynne Matallana

Founder of *FM Aware* magazine and National  
Fibromyalgia Association, and author of *The  
Complete Idiot’s Guide to Fibromyalgia*

### Health Fair Silent Auction

Volunteers needed! Please call the FMAH  
Information Line at 713-664-0180 or e-mail us  
at [FMAHouston@yahoo.com](mailto:FMAHouston@yahoo.com).



# The FMAH Store

All information is presented for informational purposes only and reflects the views of the authors.

## BOOKS:

***The FM Help Book***, Jenny Fransen, R.N., and I. Jon Russell, M.D., Ph.D. Provides many practical ways to cope with FM, including how to improve sleep, develop an exercise program, and manage flare-ups. Excellent resource for patients and professionals.

***The Complete Idiot's Guide to Fibromyalgia*** by Lynne Matallana with Laurence Bradley, Ph.D., Stuart Silverman, M.D., and Muhammad Yunus, M.D. This book will show you how to create a plan to combat symptoms, work with health care professionals and garner support from family and friends.

## VIDEOS:

***Anti-Polymer Antibodies: An Objective Laboratory Marker for FMS***, Russell Wilson, Ph.D., January 2005. The first blood test for Fibromyalgia is now in FDA clinical trials. Wilson explains his theory and how it can lead to new treatments.

***Advances in TMJ Treatment***, Charles Hoopingarner, D.D.S. Many FM patients also have jaw pain. Find out how it can be treated with the latest technologies.

***Fibro-What? A Hypnosis Approach***, Michael Schuman, C.Ht. Schuman has a special interest in medical hypnotherapy. Learn how hypnosis works and how it can help relieve your pain.

***Treating Fibromyalgia***, Robert Bennett, M.D., and Sharon Clark, M.D., Oregon Health and Science University. This tape features two internationally renowned FM researchers. Bennett discusses "What you and your doctor need to know about treating Fibromyalgia," and Clark's topic is "The risks and benefits of exercise."

***Social Security Disability and FM***, Pi-Yi Mayo, Attorney, June 2004. Mayo is an expert in Social Security and Elder Law. In this tape, he clearly explains the process for applying for disability benefits and he answers questions from the audience.

***Fibromyalgia and Headaches***, Tad Seifert, M.D., April 2004. Seifert is a neurologist specializing in headaches. He discusses diagnosing and treating headaches, a common component of FM.

## MISCELLANEOUS:

**Lapel Pin.** NEW! Our logo is now a lapel pin. In full color, it reads "Piecing Together a World With Hope" and shows the puzzle pieces of research, education, support, and vision. It's a great way to spread the word about FMAH and Fibromyalgia. Only \$3.50 to show your support.

**Free Kroger Card.** Do you shop at Kroger? Each time you check out, hand your Kroger Share Card to the cashier and we'll receive a donation of 1% of your purchase. Send us an SASE, and we'll be happy to send you as many as you need.

***The Fibromyalgia Connection.*** Newsletter published by The Fibromyalgia Association of Houston. Free to Texas residents; others may view it free of charge on our Web site or send \$10/year for three issues.

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### FMAH T-Shirts

Help raise FM awareness! The front of the T-shirt tells who we are, and the back shows the main symptoms of FM. A picture is worth a thousand words, and this T-shirt can help explain FM for you.



(circle size):

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