

Mary's Message

Wouldn't it be wonderful if one little pill could make us instantly feel healthy and energetic? I would love to swallow a pill and not have to do anything else to get healthy. How easy that would be! I could eat whatever I want and get my exercise by lifting the glass of water.

I think that most of us are secretly hoping to get a magic pill when we go to the doctor. We expect medicine to solve all of our health problems so that we don't have to make any changes in our lives. Unfortunately, managing fibromyalgia isn't that simple.

Long ago, I realized that medicine alone was not enough. It's an important part of my treatment, but so is exercise, massage, and stress management. I learned that I needed to take control of my life, and I couldn't blame anyone else for being out of shape and stressed out.

I'm blessed that I can get a regular massage. If money is tight, there are local massage schools that offer inexpensive massages. You don't have to join a fancy gym to exercise. Walking is a good start, or do the stretches on our movement DVD "Strength Through Movement." Whatever you do, start slowly and work up. Taking slow, deep breaths can help when you're feeling stressed. Of course, a counselor can give you individual help in a few sessions. Call us if you would like referrals.

While we hope for miracles, we can get moving, breathe, and call the Information Line for support. It won't happen overnight, but we CAN feel better.

Take care,
Mary Harper
President

In Memoriam: Anne Harris

By Mary Harper

When the Air France jet fell out of the sky last June, FMAH lost a great friend and volunteer, Anne Harris. Anne and her husband, Mike, were on their way to France and Spain for a business meeting and vacation. They had been living in Brazil since 2008, where Mike worked for an energy company.

Anne suffered from chronic fatigue syndrome and fibromyalgia. Although she was forced to quit working as a physical therapist because of illness, she still felt compelled to help others. Anne contacted us and volunteered to answer our Information Line one week a month. She proved to be a loving and compassionate listener to those who called the line. Anne gave information about the association, made referrals to doctors, and provided support to all. Even when she was so ill that she could barely get out of bed, Anne still returned calls and listened patiently.

We at FMAH were saddened when she called to tell us that she

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Fibromyalgia Association of Houston

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.

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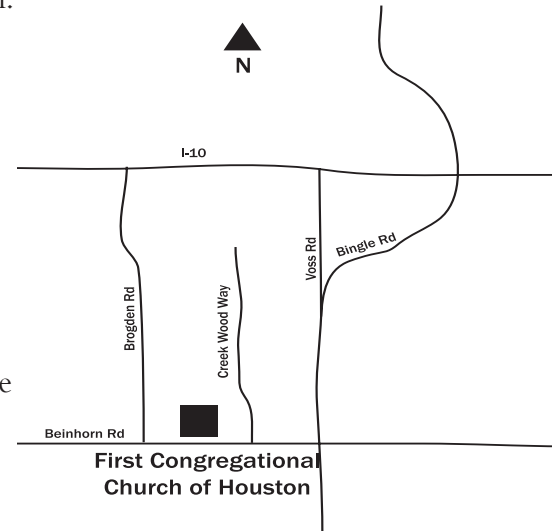
For more information about fibromyalgia, call the FMAH Information Line at 713-664-0180. A volunteer will return your call.

Support Group Meeting Schedule

We meet at the First Congregational Church of Houston and greatly appreciate the space they provide for our meetings; however, FMAH is not affiliated with any church.

All meetings are free and open to the public. Friends and relatives are always welcome.

FMAH reserves the right to substitute speakers if necessary, so for up-to-date information, please call the Information Line at 713-664-0180 or visit us online at www.fmah.org. Parking is free in the church lot.



LOCATION:

The First Congregational Church of Houston
 10840 Beinhorn Road (Just south of I-10 at the Voss/Bingle exit)

ROOM:

Assembly Room: Follow the covered walkway. Signs will be posted.

DAY:

Second Saturday of the month.

TIME:

1-3 p.m. New members are encouraged to come early.

September 12:

“Physical Medicine: A Physiologist’s Approach to Fibromyalgia”
 Helen Schilling, M.D.

October 10:

“Is there anything new about fibromyalgia?”
 Robert Walker, M.D.

November:

Canceled. Happy Thanksgiving!

December 12:

Potluck Lunch and Holiday Exchange Party

September

What is physical medicine? How does that specialty differ from “regular” doctors? We are very pleased to welcome back **Helen Schilling, M.D.** She was our guest speaker at our FM Awareness Day 2008 celebration. Dr. Schilling is a psychiatrist in private practice in north Houston. She is always willing to answer your questions, so please join us on Saturday, September 12, at 1 p.m.

October

Our speaker this month is **Richard Walker, M.D.** He will tell us what is new about fibromyalgia. Dr. Walker has several specialties, including integrative and environmental medicine. He is a member of the American Board of Clinical Metal Toxicology. It will be interesting to hear his views about possible connections between illness and the environment. Come for a very interesting meeting on Saturday, October 10, at 1 p.m.

November

Meeting canceled. Happy Thanksgiving.

December

Since our meeting room includes a big kitchen, we decided to have a potluck lunch and white elephant gift exchange for the last meeting of the year. We'll begin the festivities at noon.

FMAH will provide drinks, and President Mary Harper has promised to bring a big pan of lasagna. Please bring whatever food you like, and let's see what shows up. After lunch, we'll have the gift exchange. Bring a wrapped gift worth \$10 or less 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. If you can't afford a gift, or forget to bring one, don't worry. We always have extras on hand. **Note the unusual date and time: Saturday, December 12, at noon.** We hope to see you for a fun afternoon.

Donations

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.

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The following individuals made a donation in memory of Anne and Mike Harris.

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* Indicates donations of \$50 or more. Thanks to all of you!

We have new e-mail addresses to better serve you. E-mail us at info@fmah.org or to contact us about the newsletter, fmc@fmah.org.

Facing Adversity Together: A Couple Faces Chronic Illness

By Jamey Lacy July

We were living the American dream, working from our beautiful home in a lovely tree-lined suburb of Houston. My husband, William, was a successful relationship author with multiple speaking engagements here and abroad. I'd recently left my business directing Houston's first full-scale personal training and physical reconditioning studio to concentrate on writing and speaking on wellness issues.

In previous years, I competed in women's bodybuilding competitions, qualifying for nationals. I discontinued athletic competition because I believed in whole healthy living and refused to take performance-enhancing drugs.

I was featured often as a spokesperson and model in fitness magazines and as a swimwear model. I did not know it at the time, but my body had been exposed to very toxic chemicals, and, within a few years, I had developed an unusual connective tissue condition (CTD) that some doctors and health insurers referred to as fibromyalgia.

Although later, the CTD would be categorized as "undifferentiated" or "mixed" connective tissue disease, one doctor

said, "Just think of it as fibromyalgia squared."

Even though I looked very healthy, fit, and vibrant, I was going through terribly painful "flare-ups," and I was also diagnosed with two autoimmune diseases: atypical lupus and Reynaud's syndrome. I eventually left my business to minimize my workload and stress. I was able to write and speak part time, and to my great joy, my health did improve and symptoms diminished. This was about the time that I met my husband, William.

Within three to four months, we knew we were ready to share our lives together as a couple. But I also reminded William of my health status and that my condition could get better and go into remission or, possibly worsen.

He said, "Jamey, I could marry a young woman tomorrow in perfect health and she could get hit by a car the next day. Nothing is guaranteed in life — especially not our health." How could I not love this man?

Fast forward about 3½ years into our marriage when we were truly living what most would consider the American dream. Then, without warning, our dreams turned into a nightmare when one weekend I bathed one



William and Jamey July

of our dogs that had become ill. I began experiencing a whole new set of health challenges from low-grade fevers, rashes, headaches, fatigue, and achy joints to swelling around my eyes. My COBRA benefits had run out, and I could not get health insurance because of my "preexisting CTD/fibromyalgia."

Over the next seven years, we watched helplessly as my health slowly deteriorated while spending hundreds of thousands of dollars out-of-pocket searching for a diagnosis. By the time we discovered the source of the disease (*Rickettsia*, a form of Lyme disease transmitted by a flea or mite), we'd lost our home and our beloved dogs and were fighting for my life. With such a

late diagnosis, conventional treatments of IV antibiotics proved ineffective and I developed torturous secondary conditions that drastically affected my immune system and skin.

Our lives had been turned upside down, and the storm raged on. On one of my many visits to the ER, an internist placed me on megadoses of prednisone. I experienced virtually every possible side effect from the medication, including osteoporosis, spontaneous multiple fractures (bones in my ribs, hips, and sacrum simply cracked without any injury or impact), cataracts which required eye surgery, extreme edema from head to toe that grossly distorted my appearance, hypertension,

and mild heart attacks! Most recently, I've had recurring bouts of pain and fatigue from the CTD and the Rickettsia.

Although there were plenty of days when we felt we could not go another step, our faith, determination, and openness to grace helped us get through one health crisis after another and the physical, emotional, and financial devastation that ensued. We gradually learned ways to find laughter in the tears and peace in the storm. That's why we chose to write *A Husband, A Wife & An Illness: Living Life Beyond Chronic Illness*. We want to provide a source of empathy, hope, inspiration, and information to other couples and anyone in a patient-caregiver relationship. This is

also the only book that is written from both perspectives, and it offers some great questions, ideas, and exercises to help the patient spouse and the caregiving spouse live life beyond illness.

The book, *A Husband, A Wife & An Illness: Living Life Beyond Chronic Illness*, and, the authors' DVD, *In Sickness & In Health: Keeping Love Alive in the Midst of Chronic Illness*, are available for sale at the monthly support meetings. You can read excerpts from the book and view clips from the DVD at www.couplesfacingillness.com.

Order both the book and DVD on page 11 of this issue.



Anne and Michael Harris

The FIBROMYALGIA Connection

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was moving to Brazil for three years, but happy that she promised to "get back on the phones" when she returned. We will miss her cheerfulness and willingness to help others.

Her family generously asked that, in lieu of flowers, donations be made to FMAH. Those contributions have covered the cost of this newsletter, and so we dedicate this issue in honor of Anne Harris's memory.

Visit FMAH online to keep up with latest news or to learn more about fibromyalgia.



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Using Dietary Supplements Wisely

Many people take dietary supplements in an effort to be well and stay healthy. With so many dietary supplements available and so many claims made about their health benefits, how can a consumer decide what's safe and effective?

About Dietary Supplements

Dietary supplements were defined in a law passed by Congress in 1994 called the Dietary Supplement Health and Education Act (DSHEA). According to DSHEA, a dietary supplement is a product that:

- Is intended to supplement the diet
- Contains one or more dietary ingredients (including vitamins, minerals, herbs or other botanicals, amino acids, and certain other substances) or their constituents
- Is intended to be taken by mouth, in forms such as tablet, capsule, powder, softgel, gelcap, or liquid
- Is labeled as being a dietary supplement

Research has shown that some uses of dietary supplements are effective in preventing or treating diseases. For example, scientists have found that folic acid (a vitamin) prevents certain birth defects, and a regimen of vitamins and zinc can slow the

progression of the age-related eye disease macular degeneration. Also, calcium and vitamin D supplements can be helpful in preventing and treating bone loss and osteoporosis (thinning of bone tissue).

Research has also produced some promising results suggesting that other dietary supplements may be helpful for other health conditions (e.g., omega-3 fatty acids for coronary disease), but in most cases, addi-

tional research is needed before firm conclusions can be drawn.

Federal Regulation of Dietary Supplements

The federal government regulates dietary supplements through the U.S. Food and Drug Administration (FDA). The regulations for dietary supplements are not the same as those for prescription or over-the-counter drugs. In general, the regulations for dietary supplements are less strict.

- A manufacturer does not have to prove the safety and

effectiveness of a dietary supplement before it is marketed. A manufacturer is permitted to say that a dietary supplement addresses a nutrient deficiency, supports health, or is linked to a particular body function (e.g., immunity) if there is research to support the claim. Such a claim must be followed by the words "This statement has not been evaluated by the

Food and Drug



Administration. This product is not intended to diagnose, treat, cure, or prevent any disease."

- Manufacturers are expected to follow certain "good manufacturing practices" (GMPs) to ensure that dietary supplements are processed consistently and meet quality standards. Requirements for GMPs went into effect in 2008 for large manufacturers and are being phased in for September - December 2009

small manufacturers through 2010.

- Once a dietary supplement is on the market, the FDA monitors safety. If it finds a product to be unsafe, it can take action against the manufacturer and/or distributor, and may issue a warning or require that the product be removed from the marketplace.

Also, once a dietary supplement is on the market, the FDA monitors product information, such as label claims and package inserts. The Federal Trade Commission (FTC) is responsible for regulating product advertising; it requires that all information be truthful and not misleading.

Sources of Science-Based Information

It's important to look for reliable sources of information on dietary supplements so you can evaluate the claims that are made about them. The most reliable information on dietary supplements is based on the results of rigorous scientific testing.

To get reliable information on a particular dietary supplement:

Ask your health care providers. Even if they do not know about a specific dietary supplement, they may be able to access the latest medical guidance about its uses and risks.

Look for scientific research

findings on the dietary supplement. NCCAM and the Office of Dietary Supplements, both a part of the National Institutes of Health (NIH), as well as other federal agencies, have free publications, clearinghouses, and information on their Web sites.

Safety Considerations

If you are thinking about or are using a dietary supplement, here are some points to keep in mind.

Tell your health care providers about any complementary and alternative practices you use, including dietary supplements (see nccam.nih.gov/timetotalk). It is especially important to talk to your health care provider if you are

- Thinking about replacing your regular medication with one or more dietary supplements.
- Taking any medications (whether prescription or over-the-counter), as some dietary supplements have been found to interact with medications.
- Planning to have surgery. Certain dietary supplements may increase the risk of bleeding or affect the response to anesthesia.
- Pregnant or nursing a baby, or are considering giving a child a dietary supplement. Most dietary supplements have not been tested in pregnant women, nursing

mothers, or children.

If you are taking a dietary supplement read the label instructions. Talk to your health care provider if you have any questions, particularly about the best dosage for you to take. If you experience any side effects that concern you, stop taking the dietary supplement and contact your health care provider. You can also report your experience to the FDA's MedWatch program. Consumer safety reports on dietary supplements are an important source of information for the FDA.

Keep in mind that although many dietary supplements (and some prescription drugs) come from natural sources, "natural" does not always mean safe. For example, the herbs comfrey and kava can cause serious harm to the liver. Also, a manufacturer's use of the term "standardized" (or "verified" or "certified") does not necessarily guarantee product quality or consistency.

Be aware that an herbal supplement may contain dozens of compounds and that its active ingredients may not be known. Researchers are studying many of these products in an effort to identify active ingredients and understand their effects in the body. Also consider the possibility that what's on the label may not be what's in the bottle. Analyses of dietary supplements some-

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Medication Safety

People often combine foods. For example, chocolate and peanut butter might be considered a tasty combination. But eating chocolate and taking certain drugs might carry risks. In fact, eating chocolate and taking monoamine oxidase (MAO) inhibitors, such as Nardil (phenelzine) or Parnate (tranylcypromine), could be dangerous.

MAO inhibitors treat depression. Someone who eats an excessive amount of chocolate after taking an MAO inhibitor may experience a sharp rise in blood pressure.

Other foods that should be avoided when taking MAO inhibitors: aged cheese, sausage, bologna, pepperoni, and salami. These foods can also cause elevated blood pressure when taken with these medications.

There are three main types of drug interactions:

- Drugs with food and beverages
- Drugs with dietary supplements
- Drugs with other drugs

“Consumers should learn about the warnings for their medications and talk with their health care professionals about how to lower the risk of interactions,” says Shiew-Mei Huang, Ph.D., deputy director of the Office of Clinical Pharmacology in the Food and Drug Administration’s (FDA) Center

for Drug Evaluation and Research (CDER).

Drugs with Food and Beverages

Consequences of drug interactions with food and beverages may include delayed, decreased, or enhanced absorption of a medication. Food can affect the bioavailability (the degree and rate at which a drug is absorbed into someone’s system), metabolism, and excretion of certain medications.

Examples of drug interactions with food and beverages include alcohol, grapefruit juice, licorice, and chocolate.

Drugs with Dietary Supplements

Research has shown that 50 percent or more of American adults use dietary supplements on a regular basis, according to congressional testimony by the Office of Dietary Supplements in the National Institutes of Health.

The law defines dietary supplements in part as products taken by mouth that contain a “dietary ingredient.” Dietary ingredients include vitamins, minerals, amino acids, and herbs or botanicals, as well as other substances that can be used to supplement the diet.

Examples of drug interactions with dietary supplements include

St. John’s Wort (*hypericum perforatum*), vitamin E, ginseng, and ginkgo biloba.

Drugs with Other Drugs

Two out of every three patients who visit a doctor leave with at least one prescription for medication, according to a 2007 report on medication safety issued by the Institute for Safe Medication Practices. Close to 40 percent of the U.S. population receive prescriptions for four or more medications. And the rate of adverse drug reactions increases dramatically after a patient is on four or more medications.

Drug-drug interactions have led to adverse events and withdrawals of drugs from the market, according to an article on drug interactions co-authored by Shiew-Mei Huang, Ph.D., deputy director of FDA’s Office of Clinical Pharmacology. The paper was published in the June 2008 issue of the *Journal of Clinical Pharmacology*.

However, market withdrawal of a drug is a fairly drastic measure. More often, FDA will issue an alert warning the public and health care providers about risks as the result of drug interactions.

Tips to Avoid Problems

There are lots of things you can do to take prescription or

over-the-counter (OTC) medications in a safe and responsible manner.

- Always read drug labels carefully.
- Learn about the warnings for all the drugs you take.
- Keep medications in their original containers so that you can easily identify them.
- Ask your doctor what you need to avoid when you are prescribed a new medication. Ask about food, beverages, dietary supplements, and other drugs.
- Check with your doctor or pharmacist before taking an OTC drug if you are taking any prescription medications.
- Use one pharmacy for all of your drug needs.
- Keep all of your health care professionals informed about

everything that you take.

- Keep a record of all prescription drugs, OTC drugs, and dietary supplements (including herbs) that you take. Try to keep this list with you at all times, but especially when you go on any medical appointment. The Food and Drug Administration (FDA) has a Web site where you can get more information and download a sample medicine record: www.fda.gov/cder/consumerinfo/my_medicine_record.htm.

This article is courtesy of the FDA Web site and has been modified. To read the complete article, visit <http://www.fda.gov/ForConsumers/ConsumerUpdates/UCM096386>.

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A Husband, A Wife, & an Illness: Living Life Beyond Chronic Illness

by Dr. William July and Jamey Lacy July

At the FMAH Store (see page 11) or visit us online at fmah.org.

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times find differences between labeled and actual ingredients.

For example:

- An herbal supplement may not contain the correct plant species.
- The amount of the active ingredient may be higher or lower than the label states. That means you may be taking less – or more – of the dietary supplement than you realize.
- The dietary supplement may be contaminated with other herbs, pesticides, or metals,

or even adulterated with unlabeled ingredients such as prescription drugs.

For current information from the federal government on the safety of particular dietary supplements, check the “Dietary Supplements: Warnings and Safety Information” section of the FDA Web site at www.cfsan.fda.gov/~dms/ds-warn.html.

For More Information

You can learn more about dietary supplements from NCCAM by viewing the ex-

panded version of this fact sheet at nccam.nih.gov/health/supplements/wiseseuse.htm or ordering a printed version from the NCCAM Clearinghouse. The expanded fact sheet includes selected references and additional resources.

This article was reprinted with permission from National Center for Complementary and Alternative Medicine. To read the original article online, visit http://nccam.nih.gov/news/newsletter/2009_january/supplements.htm.

The FMAH Store

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

BOOKS

A Husband, A Wife, & an Illness: Living Life Beyond Chronic Illness, by Dr. William July and Jamey Lacy July. Provides a personal insight into the husband-and-wife dynamic as chronic illness tests their relationship. The Julys share practical tips for both the caregiving spouse and the afflicted spouse.

DVDs

Show Me Where It Hurts – Features two of our 2006 conference speakers, Patrick Wood, MD, and Lynne Matallana, president of the National Fibromyalgia Association. The video discusses cutting-edge research and interviews patients who tell their stories. It provides a great introduction to fibromyalgia and will help friends and families understand what you're going through.

Strength Through Movement – Get moving with FMAH's latest movement video featuring real fibromyalgia patients. This DVD focuses on increasing flexibility and relaxation while reducing stress. Narrated by fitness professional Leslee A. Cross, this video will get you moving!

MEETING DVDs

Acupuncture Basics, John Paul Liang, president of the American College of Acupuncture & Oriental Medicine, explaining the theory and use of acupuncture. July 2008.

Changes in Social Security Disability, Robert Hardy, attorney. Hardy is an expert in Social Security Disability law. He explains the current procedure for applying for disability benefits and discusses changes.

In Sickness & In Health: Keeping Love Alive in the Midst of Chronic Illness, Dr. William July and Jamey Lacy July. Professionally recorded live at our February 2009 meeting, this DVD is packed with over an hour of realistic information and inspiration for couples and individuals living with chronic illness.

Maintaining Healthy Relationships, Mary Jo Rapini, LPC. Being chronically ill and in pain makes keeping healthy relationships a real challenge. Mary Jo is open, frank, and quite an entertaining speaker. February 2008.

Medical Massage and You by Mike O'Quin, MMP. Learn how medical massage can help you feel better. See a demonstration of Active Isolated Stretching on president Mary Harper. August, 2009.

Reasons for Foot and Ankle Pain, Justin Jex, DPM. Many of us with FM also have foot and ankle pain. Dr. Jex explains the basics of FM and explains common problems that can add to our pain. He gives practical advice and gives coping tips. March 2008.

Water Exercise by Lisa Miller. One of the best things to help ease your pain is to get into warm water. Lisa discusses the benefits of water exercise, and gives ideas for your own water workout. April 2009.

MISCELLANEOUS

Lapel Pin. 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.

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.

FMAH Store Order Form

New Low Prices!

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<i>A Husband, A Wife, & An Illness: Living Life Beyond Chronic Illness</i>	-----	\$15.00	\$-----
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MISCELLANEOUS:

Lapel Pin	-----	\$3.00	\$-----
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Free to Texas residents. Out-of-state subscriptions: \$10/three issues.

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): S, M, L, XL, 2XL

-----	\$12.00	\$-----
	Donation:	\$-----
	Total:	\$-----

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