

The Fibromyalgia Connection

The Fibromyalgia Association of Houston, Inc.

Fall 2002

Volume 9 Number 3

FMAH Celebrates 10 Years of Service

Come join us on Tuesday, September 24, 2002, for a very special evening. Enjoy a delicious BBQ dinner of BBQ beef, chicken, coleslaw, potato salad, beans, and all the trimmings. It will be catered, so you don't have to worry about bringing any potluck dishes. The festivities will begin at 6:30 p.m. in the Fellowship Hall of St. Luke's United Methodist Church. See page 2 for directions to St. Luke's.

West University's own **Comedy Cop, Sgt. Mike Peterson**, will be our headliner entertainer. Laugh your pain away with hilarious jokes about life on the beat. According to Mike, he has two unique careers that are rarely mixed and matched - police duty and stand-up comedy. Mike is a sergeant with the West University Police Department and also performs as the Comedy Cop at local comedy clubs. He has twice been a finalist in Houston's Funniest Person contest and a semifinalist in Ed McMahon's Next Big Star talent contest and has performed live nationally on ABC-TV's *The View*. Mike has just released his first CD, called *Who's Your Grandma?* Mike says, "When I stop a driver for speeding and he makes a laughable excuse why he shouldn't get a ticket, I'm more than willing to listen because he's helping me write my next comedy bit."

Besides a great dinner and guaranteed laughter, we will have a silent auction. We will have a variety of items available, including two tickets to the Houston Ballet's *Nutcracker*. We are still accepting items for

the silent auction, so if you can donate a weekend at your mountain cabin or if you have tickets to a performance or know a merchant who could donate something, please call us at the Hotline.

As if all that weren't enough, we are planning a few surprises. Please come and help us celebrate our accomplishments. Most support and education groups don't last but a few months. FMAH has been here for over 10 years, providing help and information to thousands of sufferers.

Tickets for the evening are only \$10 each. They **must** be purchased in advance. Bring your family and friends. You can't find a better deal in Houston for a fabulous dinner plus a free show with the **Comedy Cop, Sgt. Peterson** won't give you a ticket, but you will need a ticket to join in the fun.

You may purchase your tickets by phone or by mail. To buy them by phone, call the **Hotline** at 713-664-0180. The recording will tell you that a Board Member will call you back to obtain your credit card information. We will then either mail you the tickets or hold them for you at the door.

To buy tickets by mail, look for the order form on page 19 of this newsletter. Another order form is on our Web site, www.fmah.org, if you prefer not to cut your newsletter. We have limited seating available so buy your tickets today.

2002 Meeting Calendar

Support group meetings will be held the fourth Tuesday of each month from January through October. Because of the holidays, the November and December meetings will be combined and held on the first Tuesday of December. 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. Please feel free to bring a chair cushion for your comfort. 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. For the most current information, please call our Hotline at 713-664-0180.

Location: **St. Luke's United Methodist Church, Parlor B**
3471 Westheimer, inside Loop 610

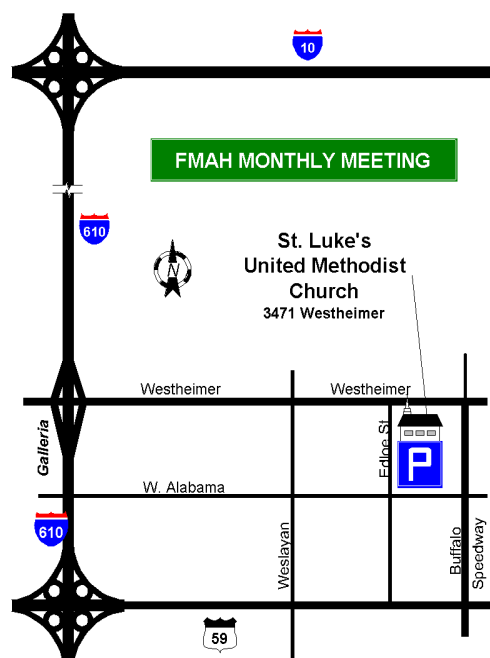
Time: **6:30 p.m.** New members, please arrive 15 minutes early to register.

September 24 **10th Anniversary Celebration**
BBQ Dinner featuring special guests and Silent Auction

October 22 **Aaron Hamilton**
Report on *Take Control of Your Life* Conference

November No meeting, but don't forget to mark your calendars for the **garage sale on November 9**

December 3 **Holiday Party**
White Elephant Gift Exchange



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Dr. Russell went on to explain the current definition of FMS as widespread pain generally characterized by unusual tenderness at a variety of body sites, persisting for a period of three months or more. This widespread pain is critical to understanding FMS.

Dr. Russell identified allodynia (unusual tenderness) as a primary characteristic of FMS pain. In research study, allodynia can be documented using a pressure gauge. Healthy normal individuals tolerate from 4 to 10 kg of pressure before they begin to experience a change from a pressure sensation to the perception of pain. By contrast, those who suffer from FMS experience pain in affected areas with only 1 to 3 kg of pressure. This poor tolerance of pressure indicates that people with FMS have low pressure pain thresholds and that feature of the syndrome meets the research definition of allodynia. Dr. Russell indicated that FMS is now the human model of chronic widespread allodynia.

With respect to identifying the cause of experienced pain, Dr. Russell stresses the importance of distinguishing between pain in the soft tissues of the musculoskeletal system and pain originating from an organ within a body cavity, for example the heart in the chest cavity. When a person complains of chest pain, the examining physician should consider the possibility that the chest pain may be related to inadequate blood circulation to the heart. On the other hand, it is important to realize that the intensity of chest-wall pain can be similar to the pain associated with a muscle injury from heart attack. The good news is that chest wall pain is much less likely to result in serious damage or risk to the person's survival. Chest-wall pain can often be reproduced by applying pressure to the affected area of the chest wall and can be eliminated, at least temporarily, by a local injection of an anesthetic medicine. The examining physician can identify an area of chest wall pain

by applying digital pressure to the affected part of the body. Dr. Russell suggested that patients who suffer from chest pain make sure that their physicians have differentiated between chest-wall pain and heart-related pain by applying pressure on the affected areas of the chest to see if the pain is coming from the outside or from within.

Twenty years ago, when Dr. Russell began looking for a biochemical cause for FMS, there was a lot of skepticism among his colleagues because the disorder was thought to be a psychiatric process. Now there is much evidence to show that FMS is an objectively demonstrable disorder of pain signal processing. Dr. Russell gave an overview of the precise mechanism of pain by explaining how pain signals are created, transmitted, received, and perceived in the normal nervous system. This process is called nociception. He then showed the ways in which the nociceptive system is abnormal in people with FMS. Pain is a protective mechanism that warns the body of the potential for tissue injury. In people with FMS, the chemical abnormalities enhance normal sensory signals from the body and convert them into pain signals. Dr. Russell identified a number of chemical factors that influence an individual's perception of pain, such as neurochemistry (the chemical processes in the central nervous system), chemical processes of the neuroendocrine system (*e.g.*, pancreas, thyroid), and genetics. Dr. Russell's research has discovered that patients with FMS maintain a different balance of key nociceptive chemicals than those who do not suffer from the syndrome.



Dr. Russell approaches the podium.

Malfunctioning nociception can lead to the sensitization of the entire central nervous system. Pain signals in the central nervous system can actually be altered such that signals that are intended to represent one sensation (*e.g.*, vibration, cold) are transformed into signals of pain. In other words, the central nervous system becomes sensitized to reading pain signals instead of signals that are supposed to represent other sensations. Dr. Russell gave three reasons for this phenomenon in FMS patients: 1) the levels of the chemicals that counteract and control pain signals are too low; 2) neurons that were intended to detect vibration or pressure convert their messages into pain signals (called central sensitization); and 3) permanent alterations of neuron connections (neuroplasticity) direct the messages of non-pain neurons to other neurons that interpret the new messages as being related to pain.



Dr. Rubin, VP & Medical Director of FMAH, presents Dr. Russell with a gift as a token of appreciation.

Dr. Russell found major differences in the levels of chemicals such as serotonin and tryptophan that counteract and control pain signals in FMS patients. Both serotonin and tryptophan were found to be considerably lower in FMS patients than in the control subjects. This means that people with FMS lack the normal resources to control or fight off pain. Serotonin is critical because serotonin levels in the brain control the levels of substance P in the brain (the lower the level of serotonin, the lower the level of substance P). Substance P in the brain then controls the levels of serotonin in the spinal cord. Serotonin in the spinal cord regulates the levels of substance P in the spinal cord where the fluid. The research demonstrated that FMS patients had elevated levels of substance P in the region of their spinal cord, as much as 75-80% higher in some cases. The production of substance P in peripheral nerves can also be enhanced by nerve growth factor which was found to be increased in the spinal fluid of people with FMS.

Both substance P and serotonin also impact the neuroendocrine system, which directly affects how the person responds to challenging or stressful situations. When those systems are not working properly, the person's ability to handle the usual activities of life can be seriously impaired. The neuroendocrine system aids the body in producing

the hormones that are needed for nearly every function of the body. This may also help to explain why many functions of the autonomic nervous system may also be dysfunctional in people with FMS.

Dr. Russell explained the importance of the neuroendocrine system and how it relates to growth hormone. Growth hormone maintains muscle function and is produced when people are in deep stages of sleep. However, since most FMS patients do not achieve normal amounts of deep level sleep, they typically have a growth hormone deficiency. Dr. Robert Bennett did a six-month study in which patients with FMS were injected with growth hormone or with an inactive placebo. After about four months of this therapy, the patients receiving the active growth hormone began to improve. One problem with this kind of therapy is that side effects can be very serious if the medicine is not properly administered and monitored. In addition, growth hormone is currently very expensive, so the cost for a year of therapy could be as high as \$12,000, making it virtually out of reach for most FMS patients. Hopefully, the cost will come down with time.

Nitric oxide (NO) is another chemical found to be overproduced in the early years of FMS when compared to people who do not have FMS. Nitric oxide is a potent body chemical that helps to control many functions of the body, including pain. Scientists believe that the greater the amount of NO, the greater the perception of pain. The research showed higher levels of NO in younger FMS patients when the character of the syndrome was developing. Perhaps the process initiated by the elevated levels of NO will continue with age even though the levels of NO eventually normalize as the person with FMS gets older.



Lecture attendees gather to purchase copies of Dr. Russell's book and collect materials provided by FMAH.

Dr. Russell is working with other investigators across the country to study members of families in which at least two members of the family experience FMS-like symptoms. The ultimate objective is to find out if there is a genetic abnormality responsible for the disorder in these families. One gene that has been reported to be abnormal in FMS is the gene that codes for a G-inhibitory protein receptor found in lymphocytes (small white blood cells). It is easy to participate in this study but does require that several members of the family go to San Antonio for a brief evaluation and blood test. The entire process takes only about two hours in a single morning for a family group. Any of our readers who think that their family might qualify for this study are urged to participate. For information on this study, call the research nurse, Wanda Haynes, RN, BSN, CCRC, at 210-615-6611.

Dr. Russell concluded his lecture by offering a reason for the extended morning stiffness experienced by people with FMS. Patients with FMS reported morning stiffness lasting from 30 minutes to four hours, comparable to the stiffness experienced by persons with rheumatoid arthritis. Generally, the morning stiffness experienced by people with osteoarthritis lasts only about fifteen minutes. Hyaluronic acid is now believed to participate in the process of morning stiffness. Accordingly, it came as no surprise when people with FMS were found to have higher

levels of hyaluronic acid in their blood than were found in the blood of health normal control subjects.

Dr. Russell was extremely generous to stay and answer all of the questions submitted by our audience on note cards. Some of the interesting facts that came out in the question-and-answer session were:

- Zanaflex is the latest drug in treating FMS pain studied in Dr. Russell's research center. It moderately reduces pain, helps improve the problem of poor sleep, and reduces the severity of the morning stiffness. The more dramatic finding, however, was that it objectively reduced the elevated level of spinal fluid substance P. If your doctor decides to give you this medicine for your FMS symptoms, you should have a blood test every month or two to check liver function.
- Regular exercise is important in FMS patients because it increases the level of serotonin in the blood, reduces the risk of heart disease, and maintains the function of muscles needed for self care as the person ages. This is something the person can do for themselves at very reasonable cost. The benefits are so substantial that one would wonder why everyone with FMS is not on a regular exercise program. The truth is that it is harder for people with FMS to exercise than it is for healthy people. If they exercise too aggressively, they pay with more pain the next few days. The trick to effective exercise is to do it regularly (every other day or three days per week) and build up the activity gradually. Dr. Russell recommends walking-in-place in a swimming pool with water to your upper chest level. This is particularly important for people who are overweight or have arthritis in the weight bearing joints (hips, knees, ankles) of their legs.
- A nationally advertised sleep device called the "Cuddle Ewe Underquilt" was critically tested in Dr. Russell's research center and found to improve both sleep and body pain. The benefit probably came from reducing the pressure on tender points during sleep.
- About 40% of FMS patients suffer from depression. The depression is generally linked to the pain. Therefore, most of the depression associated with FMS is situational. When the pain is controlled, the depression is removed or lessened as well. There is evidence to suggest that substance P is involved in the depression of FMS and controlling its activity could substantially reduce the severity of the depression with this condition.
- Most of the medications mentioned in Dr. Russell's lecture are not safe to take while a woman is pregnant or breast-feeding. Any women with FMS who is pregnant or is nursing a baby should consult her gynecologist before taking any medicine to treat the FMS symptoms. Having untreated FMS does not cause any known affects on an unborn fetus.
- Chili peppers contain capsaicin, which can reduce the severity of body pain in FMS when applied to the skin. There are now commercial creams containing capsaicin that can be purchased over the counter without a prescription. When they are repeatedly applied to the skin of a person with FMS, the levels of substance P are reduced in the nerves from that area and the local pain is decreased as well. Everyone who has eaten a jalapeño pepper will recall the resultant burning of the tongue and oral mucosa. The same kind of burning pain would be experienced with the capsaicin cream if

it were accidentally touched to the delicate membranes of the eye or of the perineal area. Disposable plastic gloves are now available and reasonably priced, so application of the cream should be done by a person wearing such protection. People who take a hot shower hours to days after applying the capsaicin cream to their body experience a hot sensation in the treated area of skin. The analgesic benefit of capsaicin cream would be lost within a few days of discontinuing therapy, so its use has to be maintained every day to remain effective.



During the break Dr. Russell took time to answer patients' questions.

- There is no research evidence to suggest that any narcotic medication is effective for the pain of FMS. The bigger problem is that FMS is a chronic condition and people with FMS are likely to live long enough to develop physical dependence upon the narcotic. The dosage needed to manage the pain must periodically be increased and eventually the person feels the need to withdraw from all narcotic medication. That withdrawal can be worse than the FMS symptoms. For that reason, Dr. Russell does not treat FMS with any narcotic medicine, even Tylenol with codeine or vicodin. One helpful medicine that may have a minor effect on a spinal fluid narcotic receptor (but also works by increasing availability of serotonin and norepinephrine), is called

tramadol or Ultram. In dosages of about 100mg three times daily, the majority of FMS patients experience considerable relief from their body pain. Dr. Russell recommends that this medicine be started slowly, like one tablet at bedtime for about two weeks before the dosage is increased by about one tablet every four days until the average patient is taking two tablets two or three times per day. About 10-20% of patients with FMS, experience nausea and weight loss with this medicine, and cannot tolerate its use, but most of the remaining FMS patients will benefit considerably from it. Both Ultram and its stepchild, Ultracet (Ultram combined with Tylenol) were tested in Dr. Russell's research center in San Antonio.

- Dr. Russell speculates that within five years, the first of several new medicines will be given approval by the United States Food and Drug Administration specifically (as an official indication) for the treatment of FMS. He expects that the first drugs to be approved will be agents that increase the availability of norepinephrine and serotonin to inhibit pain signaling in the spinal cord. Eventually, medicines in the class of anticonvulsants will also be approved for this purpose because they can reduce the intrinsic level of pain nerve activity. He further predicts that several different types of therapeutic agents, each one designed to target a different neurofunctional abnormality in FMS, will be used in combination to control the varied manifestations of the disorder. With focused therapy, the dosages of all medications can be low enough to avoid side effects from any of them.

The initiating causes of FMS have consistently eluded physicians and researchers. Work has continued, however, because science demands objective evidence. The

chemical abnormalities in FMS patients documented by Dr. Russell and other researchers may represent the first of many long-awaited breakthroughs toward a better understanding of this enigmatic medical condition. Their efforts to identify objective abnormalities in FMS may well have altered the course of treatment for FMS as well. This awakening in the scientific community has kindled a new hope for those whose lives have been so dramatically altered by this painful syndrome.



Dr. Rubin; Toby Robbins, Executive VP; and Mary Harper discuss Dr. Russell's presentation.

Reviewed and edited by I. Jon Russell, M.D., Ph.D. FMAH appreciates Dr. Russell's kind assistance in the preparation of this article.

It is hard to capture all the vast details of Dr. Russell's presentation in this article. CDs and tapes of Dr. Russell's lecture can be ordered for \$12.50. Please see the form on page 23.

Fibromyalgia: Facing the Future

Mary Harper, President, FMAH

The National Fibromyalgia Partnership of Washington, D.C., held their first national conference in May in Orlando, Florida. Janet Gingell, Vice-President of Volunteers, and Mary Harper, President of FMAH, flew to Orlando for the weekend conference. Mary was invited to be on a panel of support group leaders Friday night, and it was wonderful to meet leaders from Maine to Florida. The other three members of the panel told their stories and discussed topics of interest to those newly diagnosed. Mary developed a practical handout, the *Comfort Checklist*, and discussed some ideas for helping oneself to feel better. See the *Checklist* following this article.

University of Florida College of Medicine researcher Roland Staud, M.D., presented his findings on "Abnormal Central Pain

Processing Mechanism in Patients with Fibromyalgia." Dr. Staud used a functional MRI to see if FM patients process pain differently from normal healthy controls. He found evidence that shows there is definitely a neurological abnormality present, and that FM pain cannot be attributed to psychological abnormality. The central nervous system "remembers" pain longer than normal, which can help explain why FM pain is widespread and not just in a specific area of the body.

Thomas Romano, M.D., Ph.D., of Wheeling, W.V., discussed his specialty, "Post-Traumatic Fibromyalgia: The Scope of the Problem and Practical Solutions." He believes that there is no doubt that FM can be caused by a trauma. While most people who have suffered an injury recover unevent-

fully, there are some who do not recover and who develop widespread pain that gets worse with time. Dr. Romano said that a careful history and physical exam by an experienced examiner is very important to making the diagnosis, since results of MRI or CT scans are normal.

Licensed Massage Therapist and FM patient Deborah Roberts had some important points to make about posture. It's critical to have correct posture and to start by keeping your head up. She feels that you must have a sense of your weight, body position and movement. That sense will tell you whether you are relaxed, tense, awkward, or graceful. By monitoring your body position, you will realize quickly when your muscles are working too hard to maintain awkward posture. Ms. Roberts said that to strengthen your core stability, you need to "pull in your belly button" and straighten your back. Her recipe for well-being includes massage, gentle stretching, movements to develop posture, good nutrition, a feeling of self-worth, giving yourself positive statements, having fun and breathing deeply.

The lead investigator for the national study on the genetics of fibromyalgia, Jane Olson, Ph.D., spoke on "The Genetics of Fibromyalgia: The Fibromyalgia Family Study." She believes that FM does run in families, and that a woman whose sister has FM has a five to 10 times greater chance of FM herself. The study, funded by the National Institutes of Health, will be completed in September 2003. They hope to have 160 families participate. Dr. Olson will be studying the entire human genome for FM genes. While it is too early for any data to be generated, it is not too late to participate. I. Jon Russell, M.D., Ph.D., of San Antonio is also an investigator and is looking for families in Texas. If you have at least two close family members (e.g. mother-daughter) who have FM, and would be interested in going to San Antonio for the study, Dr. Russell would

like to hear from you. For more information, call Dr. Russell's research nurse, Wanda Haynes, at The University Clinical Research Center. That number is 210-615-6611.

What do you do for fun? That was the question that Carol Burckhardt, R.N., Ph.D., posed to the audience. Dr. Burckhardt said that when she asks that question of FM patients, she most often gets a blank look. One of her patients said that living with FM was like going through life on a yellow light — always living with caution, unsure of what to do. Dr. Burckhardt emphasized that while FM is chronic, everyone has the capacity to get better. Improvement will be a step at a time, and relapses will happen. She discussed how to "think non-negatively." One needs to learn how to monitor one's stream of thoughts, identify beliefs and attitudes, and then subject those beliefs to the laws of reason. Dr. Burckhardt suggested these examples of "non-negative thinking":

"Is this thought useful? Does it help me feel better?"

"What are the chances that this terrible thing will happen?"

"I think of ways that I have been successful in the past in decreasing my pain."

Besides the benefits of changing the way one views a situation, Dr. Burckhardt discussed coping statements, breathing techniques, and how to make changes in your life.

Dr. Burckhardt had some final words of wisdom from other people with FM:

- ❖ Figure out what you can control, and **let go** of the rest.
- ❖ **Listen** to what you say to yourself day after day.
- ❖ **Recognize** that **what goes on inside yourself** is probably much more important than what goes on around you.
- ❖ Take back your life. It's all you've got.



Mary Harper, President of FMAH, and Janet Gingell, Vice President of Volunteers, at the Fibromyalgia: Facing the Future Conference in Orlando, Florida.

Comfort Checklist

You can feel better just by trying a few simple things. There may be some that you are already doing that help. If so, check them off and pat yourself on the back. Other ideas may be new to you. Give them a try. Most are free or a matter of making wise choices.

Clothing: Free of tight elastic? Comfortable underwear? Well-fitted bra?

Shoes: Low heels? Room for your toes? Comfortable when you first put them on?

Jewelry: Lightweight necklaces and earrings? Try a scarf or pin instead.

Purse: Give yourself 10 points if your purse weighs less than two pounds.

Men: Keep your wallet out of your back pocket.

Vacuuming: Try a new lightweight vacuum, or better yet, have someone else do the chore.

Ceiling Fans/Drafts: Don't spend time under a ceiling fan, especially while sleeping. If you're in a draft, move to another area.

Take a beach ball, put in ONE puff of air, and sit on it while driving, while flying, or anytime you'll be sitting for a while.

Keep moving. Change positions often. If you've been standing, sit down. Don't stay in one position for any length of time.

If flying, get up and stretch every hour. Drink LOTS of water, as flying dehydrates you.

If driving, stop every 1to1½ hours. Do some simple stretches before starting again.

If the seat belt bothers you, try attaching a large binder clip to the shoulder strap to prevent it from retracting all the way. It helps avoid pressure, yet will protect you in an emergency.

Keep smiling. It takes many fewer muscles to smile than to frown, and it will make you and anyone you meet happier.

Success Story

Aaron Hamilton,
VP-Patient Education, FMAH

In the last issue I started a column to feature stories about our members who had struggled with FM but who had found ways to overcome the challenges of this everyday obstacle. I started the column with my own story, and I want to thank all of those who expressed their appreciation for the piece. I am glad that many of you found encouragement from it. That is what I am hoping this column will continue to do.

However, I did not receive an overwhelming response of volunteers offering to tell their own success stories for this edition. Keep in mind that by sharing your story, you are offering hope to others. Please call the Hotline: 713-664-0180 and ask for Aaron, or e-

mail us today at FMAHouston@yahoo.com.

Survey Results

Mary Harper, President, FMAH

Of the approximately 1500 newsletters sent out in May, only 80 surveys were returned. While the low response is a bit disappointing, the information that was provided is invaluable. We appreciate those who did take the time to answer our questions. If you lost your newsletter or forgot to send the survey in, here's another opportunity to give us your feedback. You'll find another survey on page 21. As always, your information is kept strictly confidential and you may remain anonymous.

Out of the 80 respondents, 76 were female. The most common age range was 50 to 59, with 38 people. The next most common age range was 40 to 49, with 16 responding. The youngest was under 20, and the oldest was represented by seven people in their 70s. Of the various ethnic groups, Caucasians were overwhelmingly represented, with 68 people. African-Americans were the next largest group, with five people. Of course, this is a very unscientific survey and reflects only those people who took the time to answer the questions, not the actual makeup of the group.

When asked how often they have FM symptoms, the vast majority (61) said "Always." Twelve people said "Usually," and only five said "Sometimes." Those symptoms affect lifestyle "Severely" for 23 people and "A Lot" according to 39 people. For 15 patients, their lifestyle is affected "Some." All

but three people had been diag-

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nosed with FM by a doctor.

Besides FM, almost everyone has additional health problems. The most common were osteoarthritis (27), hypothyroidism (15), irritable bowel syndrome (12), acid reflux (7), TMJ dysfunction (6) and high blood pressure (6). There were a wide variety of other ailments, including depression, anxiety disorders, sleep disorders, allergies, chronic fatigue syndrome, celiac disease, kidney disease and irritable bladder syndrome.

For those illnesses, a whopping 151 different medications were prescribed. Forty-nine people take five or more medicines. Anti-depressants were the most common type of drug used, with a total of 59 people, or 74% of the patients responding. The second most common class of drug used was NSAIDS, such as Vioxx and Celebrex, with 49 respondents taking them. Almost half (37) said that they used narcotics such as Vicodin. Drugs for high cholesterol, blood pressure and heart problems were consumed by 31 people. Female hormones and medicines for sleep and anxiety were tied, as 28 people reported their use. Prescriptions for allergies were also popular, with 27 people using them. Thyroid medications were used by 25 people. Other drugs reported were muscle relaxers, anticonvulsants, gastrointestinal medications and guaifenesin.

There was a wide range of answers to the question of nondrug treatments that patients use to gain relief. Massage was the number one response, with 36 people reporting its helpfulness. The second most common treatment was the use of hot tubs, pool exercises, and hot showers and baths. Thirty-four people said that the hot water or exercising in the warm pool was therapeutic. Next on the list was exercise, with 25 patients walking, biking, stretching or using weights. Al-

How to Reach Us: Call our Hotline for names of doctors, massage therapists, and lawyers who are sympathetic to fibromyalgia. You may also call if you just need to talk to a friendly person who cares. Our counselors are all volunteers who work very hard to answer calls within 24 hours. Please understand that they have FM, too, and sometimes have several calls a day to return. We always welcome your opinions, ideas, and suggestions.

FMAH Hotline: 713-664-0180

E-mail: FMAHouston@yahoo.com

Web site: www.FMAH.org

FMAH P.O. Box 2174 Bellaire, Texas 77402

ternative treatments, such as acupuncture, aromatherapy (using oils), hypnotherapy, biofeedback, chiropractic, supplements, and reflexology were common. Physical therapy, a TENS unit, and osteopathic manipulation were used by a few. Resting and being quiet were important to several others.

FMAH members are quite creative when figuring out what makes them feel better. Painting and drawing, deep breathing, working part time, reading, good sex, and good weather were some listed. Also included in the responses were Ben Gay cream, gospel music, prayer, faith, family support, and volunteering. (Editor's Note: FMAH has plenty of opportunities to help you feel better by volunteering.) Consuming 64 ounces of water a day and drinking pineapple juice was recommended. One person advised patients to limit the number of sodas consumed, especially the dark, phosphate-rich drinks sweetened with aspartame. An-

other said that those types of drinks make her IBS much worse, and by staying with clear sodas, she feels much better. Keep in mind, also, that sodas are simply empty calories and even the diet sodas are just carbonated water with chemicals. Try reaching for a glass of water the next time you're thirsty.

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FMAH would like to thank Scott E. Davis for his very generous \$500 donation to our organization. Mr. Davis is a Social Security and long-term disability insurance attorney in Phoenix, Arizona. Mr. Davis represents clients throughout the United States. In Social Security disability cases, a fee is charged only if his client obtains benefits. Mr. Davis invites your questions and inquiries regarding representation via telephone (602) 482-4300, or e-mail: [info@scottdavispc.com](mailto:info@scottdavispc.com).

## Maintaining a Positive Attitude: Ten Strategies

Deborah A. Barrett, Ph.D.

[www.Paintracking.com](http://www.Paintracking.com)

"Have a positive attitude." How many times have we heard that one? While our emotions can not cause fibromyalgia or chronic fatigue syndrome, they no doubt affect our symptoms. But how can we maintain good thoughts when our bodies feel so lousy? This challenge, of course, does not pertain exclusively to chronic illness, but to any time when things do not go as we wish. But in the case of ongoing illness, seeing the positive presents a continuous struggle.

Yet our moods are not perfectly correlated with our physical state. Most likely we can all recall times that despite much pain or fatigue, we were able to cope and even achieve high spirits. Perhaps the weather

was perfect, good friends visited, we just accomplished something or helped somebody, making us feel good about ourselves. Other times, depression seems to take hold even when our physical discomfort is at a manageable level. Why is this? Answering this question is the key to finding optimism.

To me, the vicissitudes of fibromyalgia feel like a swim in the turbulent sea -- sometimes it seems we have fallen and the waves continue to crash on our heads, as we fight to rise, only to be knocked down yet again. But that same ocean sometimes allows us to find a wave we can ride smoothly to the shore.

What can we do when we feel under the waves? How can we find the strength to

climb back on top, and the patience to know that we will? Here are ten cognitive exercises I use to maintain the most positive attitude I can:

**1. Expect bumps!** It is important to acknowledge that we will sometimes feel down. Who wouldn't in our condition? But by expecting rather than dreading down time, such periods become more tolerable. In addition, recognizing that we will have blue periods helps keep them in perspective. We will be able to say to ourselves, "I was depressed before, and got out of it; this time, too, it will pass." It is easy to forget that before our illness, there were times we felt down. Now these periods are wrapped up in our medical problems; but everyone gets depressed some of the time. After accepting that we will sometimes feel sad, and even experience self pity, we can concentrate on ways to shorten these periods and make them fewer and farther between.

**2. Track the changes.** Keeping track of moods helps put ups and downs into perspective. During your best times, make a conscious attempt to capture the feeling. Leave notes on your wall attesting to the way you feel. Living with chronic illness easily creates a Jekyll-and-Hyde persona, where your optimistic self and your flare-up self are not sufficiently acquainted. When we feel bad, it becomes quite difficult to imagine that things can be otherwise. Similarly, during times of improvement, it's amazing how quickly we may forget how bad a previous period was, making subsequent flare-ups not only intolerable but shocking. Counting and measuring the duration of the bad times -- as well as the good ones -- can put them into perspective. It may be that over time, our worst occurs about once a month, although it feels much more frequent. This knowledge is empowering, because we can remind ourselves that a bad

flare is, for example, our monthly temporary setback, and find ways to ride it out until our baseline returns.

**3. Stockpile fun distractions.** We all need to keep lists handy of the things that make us happy. One of the cruelties of our condition is that when we need distractions most, we are least equipped to seek them out. For this reason it is important to compile a list of our favorite activities when we are feeling optimistic to be used when we most need them. People with fibromyalgia often describe how even their worst pain can be put on a back burner, so to speak, when they become engrossed in an activity. This is not only a psychological but a physiological response: our brains can only process so much input at once. When we are engrossed in a beautiful movie, talking to a good friend on the phone, or listening to our favorite music while lying on a heating pad or in the bathtub, we can trick our pain receptors into leaving us alone! Meanwhile improvements in spirit have an added impact on our entire well-being. Laughter is good medicine; while dwelling on our troubles tends to compound them.

**4. Shape your perspective.** Is the glass half empty or half full? Perspective determines, quite literally, how we view the world. Having a chronic illness creates an ambiguous construction of reality for us. Am I, for example, a successful cripple or an unsuccessful professional? In American culture, much emphasis is placed on independence, individualism, and achievement. Through this lens, developing a condition that makes us feel more dependent and less productive is likely to be a huge disappointment. Yet as we get older, it becomes more likely that we, or somebody close to us, will experience debilitating problems. People are often forced to adapt to sudden, new conditions by adopting a perspective that accommodates change. Our perspectives are shaped by the comparisons we make and the expectations they create. Consider, for example, the im-

migrant who had been practicing medicine in his home country, but flees to the US to escape a repressive political regime. Here he works as a janitor; after years of medical study, he has lost a prestigious and rewarding occupation. Yet he is thankful for the opportunity to work and wakes each day driven by hope, perhaps, of a better future for his children. Yet his difficulties are also quite apparent. What keeps his spirits up and makes him thankful rather than bitter? His perspective.

**5. Create a new self.** If we hang on tightly to the "old self" we were, finding the value of our "new self" becomes increasingly difficult. (We may even exaggerate how fit that person was: "I didn't need any sleep, I never felt bad, I could do anything!"). This does not mean we should totally discard our previous conception of self; rather, we need to find a way to integrate the two. In other words, we should seek to find in our new bodies new ways to enjoy and experience the things that we had done before. Consider all the aspects of yourself that you like, and the things that you most want to do; then step by step, find ways to achieve as many of these as you can. At the same time, recognize that our expectations must shift so that we can once again meet them.

**6. Don't forget the good stuff.** While the physical symptoms of fibromyalgia can feel all-encompassing, there are other parts of our life--our social relationships, passions, family -- that also exist. By focusing on the positive aspects of our life, we become more aware of how many there are: the friends that stuck by us, the things we still enjoy, and the accomplishments we have been able to make, however small, under very different conditions. Because each task now represents a challenge, we should celebrate whatever we manage to accomplish. As we have been told many times, if we shorten the list and pace ourselves whatever we do eventually adds up to something to be very proud of.

**7. "Oy, it could be worse."** (The Jewish mantra). As comparisons shape our view, it is helpful to find comparisons that will provide a fuller appreciation for what has befallen us. OK, the "eat because children are starving in (fill in the developing country)" did not work for you as a child. But try to think of it this way: Many bad things happen in the world. The odds are that some of them will happen to us. Not because of anything that we have done, but because, as the saying goes, stuff happens. It takes only a short view of the evening news to remind ourselves of the horrors occurring every day. So, this is what has happened to us. We too were caught. Let us examine what we have: (a) We know our condition is not terminal, so we need not begin contemplating our pending mortality. (b) As bad as we sometimes feel, our underlying condition is not going to get worse. We have already experienced the worst, and, to our credit, have gotten through it. (c) Although few people achieve permanent remission, many improve significantly. As we understand how our actions and emotions influence our general well-being, we can find ways to partake in more and more activities.

**8. Keep the hope alive!** There is so much room for hope. It has only been since the 1990s that our condition has acquired any legitimacy from the medical community. We are in a far better position than the generations before us who suffered without ever receiving validation. We know much more about the important roles of exercise, medication, stretching, pacing and meditation to bring relief and a sense of control. Furthermore, as medical research increases, it is only a matter of time before better therapies (and perhaps even a cure!) are introduced.

**9. Lean on me!** A single most important predictor of how we do is the support network we create. We certainly appreciate what it means when someone helps us when we feel especially lousy. Make sure that, within your means, you continue to be a

good friend to those you care about. We still have lots to give. During a good moment, write to a friend that you are thinking about her. Help your family and friends find ways to maintain their relationship with you. Invite them to your place to eliminate traveling (and do not worry what your place looks like! They came to see you, not your house-cleaning abilities). Try to be open with family members, while at the same time supportive of their needs. Put yourself in their shoes as often as possible -- it can be scary to have someone you love be sick! Also make sure to seek help outside of your immediate circle so as not to drain your closest friends and family. There are now all sorts of support groups, both live and in virtual computer space.

**10. Indulge whenever you can.** We have lots of time to focus on our thoughts. Most people do not have the luxury of taking time to relax and think. OK, we did not ask for these "time outs." They are demanded by the

needs of our bodies. Nevertheless, we have control over how we use this extra time. Instead of dwelling on what our bodies are not doing, give your fantasy full liberty. Turn these rest periods around to be indulgent time. In our mental playground, we can practice dance steps we used to know (for there will be some times we can dance!). We can use the time to think through problems we face and how we want to spend time when we are feeling ready, or we can analyze a movie we recently saw, say prayers, or mentally write a letter to a friend. The article you are now reading is a product of a spell in the middle of the night, when I lay in bed, unable to sleep. After taking steps to make myself more comfortable, I decided to think about what I would write next. I figured that if I fell asleep, great! But if not, I'd have thought through my next article. It was about this point when I, satisfied, went off to dreamland.

## Garage Sale Date Change!!

Please note that the new date for the garage sale is **Saturday, November 9, 2002**. It will still be held at the home of President Mary Harper. She lives near the Medical Center and has the perfect location for a garage sale. Two years ago, we made over **\$2500**, and we're hoping to gross even more this year.

Did you know that clutter around the house drains your energy? Just looking at the mess can cause stress, which adds to your pain. Take this opportunity to clean out your junk and gain energy. At the very least, having less clutter will make it easier to clean the house or to find that lost item. Use this as a chance to clean out your closets and drawers and donate your not-so-prized possessions to FMAH for our fabulous garage sale.

We have limited storage space, but we are accepting small donations now. You may bring your things to any meeting. If you have a pickup truck, we would be extremely happy to hear from you. In the past, we have had requests to pick up furniture or large items. We cannot promise to pick up your item, but feel free to call us and we will see if we can work something out.

We need everyone's help to make the sale a success. This is a great way to get involved with FMAH and have a lot of fun. Help is needed to organize and price the items. Pricing parties will be held in the weeks leading up to the sale. It's fun to get together and see what has been donated, so please be generous with your time and old clothes, jewelry, toys, books, junk, collectibles, or whatever you have to donate.



## Randall's Card



You can use your Randall's Remarkable Card to donate to FMAH. They have generously donated \$800 so far this year. The first time you give your card to the checker, remember to register for Charity Number **1094**. This number is encoded in your card, so you need to know only one time.

## Gerland's Advantage Card

Just give your card to the cashier when checking out, and enter the following ID number: 105500. FMAH will receive 1% of your purchase total.

## Kroger Share Card

Kroger will also make a donation to FMAH just for using their card. For those of you

new to the Share Card Program, you can pick up a card at a meeting, or call us and we will be happy to mail you one. Give the card to the checker before he or she rings up your order.

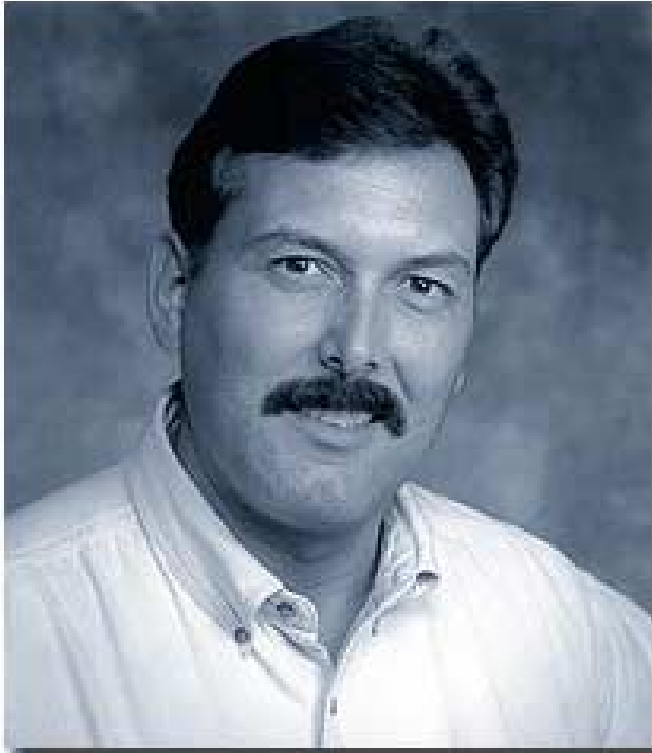
## Book/CD Drive

Clean off those bookshelves and your CD racks and help FMAH at the same time. FMAH has the opportunity to sell used books and CDs (even software) to raise money for the organization, but we need your help. Please bring your books and CDs to the meetings, and we will take care of the rest. Think of the extra space you will have when you get those shelves cleaned off.

## Garage Sale

Don't forget about our garage sale November 9. We're already taking donations and we will need lots of volunteers. See all the details on page 17.

# FMAH 10th Anniversary Dinner Tickets



**Comedy Cop, Sgt. Mike Peterson**

Please buy your tickets NOW, while you're thinking about it. We have limited seating, so don't lose your chance to join us for a very exciting evening. We are aware that it may be difficult for some of you to afford a ticket. For those in need, a limited number of reduced-price tickets are available. Call the Hotline for details.

You may purchase your tickets by phone or mail in the form below. There is also an order form on our Web site. Tickets will NOT be sold at the door. To buy them by phone, call the Hotline at 713-664-0180. The recording will tell you that a Board Member will call you back to obtain your credit card information. We will then either mail you the tickets or hold them for you at the door.

## BBO Dinner Order Form Tuesday, September 24, 2002

|                                                                             | Quantity                           | Price   | Total   |
|-----------------------------------------------------------------------------|------------------------------------|---------|---------|
| <b>Celebration Ticket</b>                                                   | _____                              | \$10.00 | \$_____ |
| NAME _____                                                                  | Make checks payable to <b>FMAH</b> |         |         |
| ADDRESS _____                                                               | Send form to <b>P.O. Box 2174,</b> |         |         |
| CITY _____ STATE ____ ZIP _____                                             | <b>Bellaire, TX 77402.</b>         |         |         |
| To pay with a credit card, please select the following: __MasterCard __Visa |                                    |         |         |
| Credit Card Number: _____                                                   |                                    |         |         |
| Credit Card Expiration Date: Month: ____ Year ____                          |                                    |         |         |
| Signature _____                                                             |                                    |         |         |

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

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Laura Apatini  
Honora Arnold  
Linda Bearden  
Katherine Berno  
Georgiana Bishop  
C.M. Brewster  
Bill Brodhead  
Alaine Butz  
Mrs. Roger  
Coughran  
\*Barbara Dale  
Dr. Beth Diestler  
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Susan Gallman  
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\*Anne Gorry  
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In Memory of Michael  
Maraggia  
Gift made by Melissa  
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Lake Jackson  
Gift made by Norma  
Plummer  
  
In Thanksgiving for Bernie  
Rosenblatt's Speedy Re-  
covery from Heart Surgery  
Gift made by \*Bernadean  
Rosenblatt  
  
\*Scott E. Davis, Attorney  
(See page 13.)

## Remembering a Special Occasion

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.

Honoree's Name \_\_\_\_\_

**Gift made by:**

Name \_\_\_\_\_

Gift Amount

Address \_\_\_\_\_

\$ \_\_\_\_\_

\_\_\_\_\_

Remembrance is honoring:

**Send notice of this remembrance to:**

Name \_\_\_\_\_

\_\_\_ Birthday

Address \_\_\_\_\_

\_\_\_ Memorial

\_\_\_ Other

\_\_\_\_\_

Please make checks payable to: FMAH  
P.O. Box 2174  
Bellaire, TX 77402

FMAH would like to ask your help in completing the following short survey. We will post the results in a future edition of the newsletter. When the survey is complete, fold it in thirds, tape it shut, and mail it in or bring it to a meeting. There is room on the back for additional comments. **All information will remain confidential!**

Tell us about yourself and your FM

Gender: Male Female

Age: under 20 20's 30's 40's  
50's 60's 70's over 79

Ethnic Group: African-American Asian  
Caucasian Hispanic Native American  
Other

I have FM Symptoms: Always Usually  
Sometimes Never Not Sure

My symptoms affect my lifestyle: None  
A little Some A lot Severely

I have been diagnosed with FM by a doctor:  
Yes No

I have other health problems: Yes No  
Please briefly describe:

List medications you take:

Nonmedication treatments that help me the most are (massage, exercise, etc.):

You and FMAH

I found out about FMAH from:

My Doctor Phone Book Friend  
Newspaper, name: \_\_\_\_\_  
Other: \_\_\_\_\_

I don't come to meetings because (check all that apply): Traffic Don't drive at night  
Too far Too tired Not interested in speakers/topics I forget Belong to Internet chat room Other: \_\_\_\_\_

I'd come to meetings if:

You and Your Doctor

Doctor's Name \_\_\_\_\_  
Specialty \_\_\_\_\_  
City \_\_\_\_\_

Are you currently seeing this doctor?  
Yes No

If yes, how long have you been seeing him/her? Less than 1 year  
More than 1 year

How would you rate your doctor's "bedside manner"? (1 is lousy and 5 is great)  
1 lousy 2 3 4 5 great

Does he/she take the time to explain tests, procedures, and treatment rationales?  
Yes No

Would you recommend this doctor to others  
with FM?

Yes

No

Additional Comments Here:

---

Return Address Optional

FMAH  
P.O. Box 2174  
Bellaire, TX 77402

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## Books, Videos, and T-Shirts

Quantity   Price   Total  
(includes shipping and sales tax)

**Books:**

*Living with Fibromyalgia: A Practical Guide to Coping* \_\_\_\_\_ \$7.00 \$ \_\_\_\_\_  
- edited by **Thomas Romano, M.D.**, and **FMAH**

*The FM Help Book* \_\_\_\_\_ \$23.00 \$ \_\_\_\_\_  
- by **Jenny Franzen & I. Jon Russell, M.D., Ph.D.**

Out-of-State Subscription to *FM Connection* \_\_\_\_\_ \$10.00 \$ \_\_\_\_\_  
(Newsletter: 1 year – 3 issues)

**Videos:**

*Social Security Disability* \_\_\_\_\_ \$10.00 \$ \_\_\_\_\_  
- by **Pi-Yi Mayo, Attorney**

*Irritable Bladder Treatments* \_\_\_\_\_ \$10.00 \$ \_\_\_\_\_  
- by **T.M. Hughes, M.D.**

*Hypnosis, Stress Management, and Pain* \_\_\_\_\_ \$10.00 \$ \_\_\_\_\_  
- by **Marty Lerman, Ph.D.**

**FM Research Advances, by Dr. I. Jon Russell:**

*2 CD set* \_\_\_\_\_ \$12.50 \$ \_\_\_\_\_

*2 Cassette set* \_\_\_\_\_ \$12.50 \$ \_\_\_\_\_

**FMAH T-Shirts:**



**L - XL** \_\_\_\_\_ \$13.00 \$ \_\_\_\_\_

**2XL - 3XL** \_\_\_\_\_ \$14.50 \$ \_\_\_\_\_

**4XL** \_\_\_\_\_ \$15.50 \$ \_\_\_\_\_

**Donation:** \$ \_\_\_\_\_

**Total:** \$ \_\_\_\_\_

Method of Payment (check one)

MasterCard    Visa  
Credit Card Number \_\_\_\_\_

Card Expires Month: \_\_\_\_ Year \_\_\_\_

Signature \_\_\_\_\_

Make Checks Payable to:

**FMAH, P.O. Box 2174, Bellaire, TX 77402**

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_ ZIP \_\_\_\_\_

Don't forget to come join FMAH...

| September |    |    |    |    |    |    |
|-----------|----|----|----|----|----|----|
| S         | M  | T  | W  | T  | F  | S  |
| 1         | 2  | 3  | 4  | 5  | 6  | 7  |
| 8         | 9  | 10 | 11 | 12 | 13 | 14 |
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| 22        | 23 | 24 | 25 | 26 | 27 | 28 |
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| October |    |    |    |    |    |    |
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| 20      | 21 | 22 | 23 | 24 | 25 | 26 |
| 27      | 28 | 29 | 30 | 31 |    |    |

| November |    |    |    |    |    |    |
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| 24       | 25 | 26 | 27 | 28 | 29 | 30 |

| December |    |    |    |    |    |    |
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| 8        | 9  | 10 | 11 | 12 | 13 | 14 |
| 15       | 16 | 17 | 18 | 19 | 20 | 21 |
| 22       | 23 | 24 | 25 | 26 | 27 | 28 |
| 29       | 30 | 31 |    |    |    |    |

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