

Rehab Continuum Report

The essential monthly management advisor for rehabilitation professionals

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Therapy for osteoporosis patients may be new trend in rehabilitation care

Multidisciplinary approach works for Maine facility

Osteoporosis is one of the most prevalent and expensive disabling diseases to strike the elderly, resulting in more than 1.5 million fractures each year and costing about \$38 million per day in direct health care expenditures, according to the National Osteoporosis Foundation in Washington, DC. Yet, there's been little interest among rehab providers in developing a specialized rehab therapy program.

That oversight is beginning to change. MaineGeneral Rehabilitation Services in Augusta has developed a new multidisciplinary osteoporosis program that includes physical therapy, occupational therapy, nutrition counseling, and consults with psychiatrists when needed.

"The idea of the program is to educate people in medication aspects of their diagnosis and other options as well as nutrition counseling and exercise," says **Cathy Bourque**, PT, MBA, rehab manager for the facility, which is part of the MaineGeneral Medical Center.

Executive Summary

Subject:

Osteoporosis is a costly, debilitating condition, and some of the public and personal health problems associated with it could be alleviated by having patients undergo a specialized rehabilitation program designed for this group of patients.

Essential points:

- ❑ A rehab osteoporosis program should provide multidisciplinary treatment, including physical therapy, nutritional counseling, consultation with a physician, and treatment with an occupational therapist when needed.
- ❑ Therapy techniques should be designed to help the patient strengthen muscles and become more flexible without causing further bone damage.
- ❑ Patient education should include a review of home safety, fall risk factors, and exercises to incorporate into daily routines.

The osteoporosis programs provide patients with information about adaptive equipment, fall prevention, and home modifications, Bourque adds.

The rehab facility began the program at the suggestion of the medical director, who noted that while a large part of the patient population had the disease and would benefit from a combination of medication, education, and exercises, no such programs were available locally, Bourque says.

"I think the diagnosis of osteoporosis is becoming more common," Bourque says. "A lot of people being diagnosed with osteoporosis seem to be advocates for their own health, and they are looking into options and things that can be done to help manage the situation."

The program's therapy is designed specifically for patients with the bone disease, and the algorithm for the program is based on exercises taught by Sara Meeks Physical Therapy in Gainesville, FL, Bourque says.

When **Sara Meeks**, PT, MS, GCS, owner of Sara Meeks Physical Therapy, began four years ago to check Internet web sites and other sources for lists of coursework offered to therapists dealing with patients who have osteoporosis, she found nothing available. Because Meeks has provided therapy to patients with osteoporosis for nearly two decades, she decided to start her own educational courses and has since taught physical therapists her techniques for helping these patients build their strength and endurance through exercise and physical therapy.

Therapists taking her courses come from rehab facilities, home care agencies, nursing homes, and other health care settings.

The program's curriculum includes the following components:

- overview of condition and bone density reports;
- risk factors and first signs;
- results of treatment;
- presentation of comprehensive program;
- exercises for postural correction;
- gait training;

- balance exercises;
- evaluation procedures;
- site-specific exercise program;
- patient education;
- scapular stabilization;
- physiorollers for stretching of hip and knee;
- performing strengthening and balancing exercises on the physioroller;
- treatment modalities;
- identified patterns of postural change;
- guidelines for exercise classes/gym programs.

Providing therapy to osteoporosis patients is a crucial part of a public health strategy to reduce fractures caused by falls, Meeks says.

"There's a terrific risk of fractures occurring throughout the population, and the cost to our health system is phenomenal," Meeks adds. "My mission is I'd like to see everybody in this entire country have the opportunity to go into a physical therapy facility or a gym and be given an exercise program that's safe for them, and that's not the case today."

The exercises Meeks recommends for osteoporosis patients differ from other physical therapy exercises because of the fragility of these patients' bones. For example, there are no exercises in which an osteoporosis patient is asked to bend the body forward, touch toes, or rotate or side-bend the trunk.

The initial exercise is a simple decompression exercise in which the patient lies on the floor with knees bent and feet flat and arms turned up. This is done once a day to take pressure off the patient's spine.

"I'm also a yoga teacher, and I think some principles of yoga have been incorporated in my program," Meeks says.

The MaineGeneral Rehabilitation osteoporosis program provides six to eight weeks of one-on-one physical therapy in which a patient's exercise program progress is monitored. Patients referred to the program typically are over age 50 and have been diagnosed through a bone density scan as osteoporotic, having a standard deviation of greater than 2.5 on a bone density scan. Patients

COMING IN FUTURE MONTHS

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■ Alternative therapies and reimbursement for rehab

■ Incorporating the Alexander Technique into therapy

often have had compression fractures in their spines and might already show signs of stooping.

Initially, patients are evaluated by a physical therapist who uses a functional assessment screening tool. During the assessment, the physical therapist might find that an occupational therapist consultation is needed, so the therapist will call the referring physician's office to discuss OT involvement.

Also, a grid camera side-view picture is taken of new patients when they begin the program and again when they complete the program so they can see how much they've improved their posture.

"A lot of people don't realize they're bent forward until they see that picture," Bourque says.

The evaluation examines posture deficits, muscular imbalances such as decreased strength and flexibility, and fall potential.

During PT sessions, patients are taught exercises that will benefit anyone with osteoporosis or who has problems with muscle imbalance, poor posture, and difficulty in doing activities of daily living, Bourque says.

By the end of the program, patients typically have strengthened their muscles and improved their flexibility.

"A lot of elderly people with osteoporosis tend to have tight hip flexors, and that's an area we spend time working on," Bourque says. "To improve their posture they need flexibility."

All osteoporosis patients and interested family members may attend an occupational therapist's educational session in which the OT discusses body mechanics, home modifications to prevent falls, and adaptive equipment. Another group discussion is led by a dietitian who talks about the importance of nutrition and answers questions

about diet, vitamin supplements, and other nutrition-related issues.

The program, which began in February 2001, is too new to have any data regarding outcomes, but there apparently is considerable interest in its services, Bourque says.

"We've passed out brochures in the community and in the hospital, and we've had a lot of patients call for information," she notes.

"We also sent out a letter to all area physicians, and the hospital here sponsors a show on the local cable station talking about health issues, and we're being scheduled to appear on that," Bourque adds.

Medicare reimburses for the therapy services, but the OT educational sessions are not billed. For a nutrition consult, the facility has to obtain a prescription from the physician, and then the dietitian does the billing, Bourque says.

"We're excited about the program, and the patients say they have been encouraged with their improvement," Bourque says. ■

Arthritis Center focuses attention on rehab options

Center has its own space starting this year

Arthritis treatment has undergone a revolution in recent years as new medications make it possible to suppress inflammation better, which may eventually reduce the rate of joint destruction or disability related to arthritis. While a great deal of media attention is paid to the pharmaceutical management of arthritis, many patients still are uneducated about arthritis treatments, especially about the role physical therapy and rehabilitation play in treatment.

Several decades ago, physicians and the public believed that people with arthritis should not exercise. Although research has proven that belief to be a fallacy, many people still are unaware of how important exercise and physical therapy are to arthritis treatment, says **Rowland Chang, MD, MPH**, medical director of the Arthritis Center at the Rehabilitation Institute of Chicago. Chang also is a professor of medicine, preventive medicine, and physical medicine and rehabilitation at Northwestern University Medical School in Chicago.

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A community survey of more than 800 respondents conducted by the Rehabilitation Institute of Chicago found that 50% of the people surveyed over age 45 reported having chronic joint symptoms. Of these arthritis sufferers, nearly 30% have never discussed it with their physicians, presumably because they erroneously believe that nothing can be done about the symptoms or consequences of arthritis, Chang says.

"We need to educate the public that arthritis is the most common cause of disability in this country and that something can be done about it," Chang says. "Patients need to know they can take some control over their own fate, since among our most useful interventions are self-management and physical activity."

This is where an arthritis center based in a rehabilitation facility plays an important role, Chang says.

The Rehabilitation Institute of Chicago's Arthritis Center opened in its own physical space in January 2001 on the ninth floor of the institute. The physical move marks a philosophical change in which outpatient services offered by the arthritis center have been enhanced and expanded.

Making arthritis a public-health issue

Chang is actively involved with the Arthritis Foundation, both at its national headquarters in Atlanta and its Greater Chicago Chapter. The Arthritis Foundation has partnered with the Centers for Disease Control and Prevention in Atlanta to create the National Arthritis Action Plan, a public health blueprint for the prevention of arthritis and its related disability.

"For the first time in history, there is a full chapter devoted to arthritis and related conditions in the *Healthy People 2010* document, which specifies the United States' public health goals and objectives for this decade. After the Arthritis Foundation took a public-health view of arthritis prevention and control, we proposed to the Rehabilitation Institute of Chicago's board that our arthritis center also take a public-health stance," Chang says.

The result is an arthritis center that provides inpatient and outpatient services, medical management, and prevention education for the public. The center also is part of the Multidisciplinary Clinical Research Center in Rheumatology at Northwestern University Medical School.

Here's a quick explanation of the center's services and mission:

1. Medical management.

"Surgery has been a very important part of treating disability as a result of arthritis for the past 25 years, and so our arthritis center is affiliated with several experienced arthritis surgeons," Chang says. "That's one of the reasons we got involved with developing a larger Arthritis Center: so we could develop more relationships with surgeons."

Physical therapy and occupational therapy play important roles in the medical management of arthritis, both after surgery and in cases where surgery is not the recommended course of treatment.

Medication is another crucial part of the medical management of arthritis patients. "Rheumatology is undergoing a major revolution presently because of the advent of biologics, a group of medicines for treating inflammatory arthritis," Chang says.

The first biologics for inflammatory arthritis to hit the market are blockers of tumor necrosis factor (TNF) -alpha, such as Enbrel, a soluble receptor for TNF-alpha, and Remicade, which is an antibody against TNF-alpha.

"These new medicines increase our ability to suppress inflammation in inflammatory arthritis, so that right now, the goal of most rheumatologists is to completely suppress inflammation," Chang explains.

In addition, there likely will be similarly effective pharmaceutical agents in the near future that will reduce the progression of osteoarthritis, which is a significant cause of disability in the United States, Chang predicts.

A fourth aspect of medical management emphasized at the arthritis center is complementary medicine. The center's staff talk to patients about nutritional supplements and what the literature says about the effectiveness of such products, some of which are being studied in clinical trials.

Other complementary medicine treatments, such as acupuncture and pool therapies, are available.

2. Outpatient services.

Most of the activities based in the arthritis center are outpatient services. Patients first are evaluated by a rheumatologist or a physiatrist; in either case, the other specialist is available for an immediate consultation, Chang says.

"So if the physiatrist sees a patient who has inflammatory arthritis that would need to be seen by a rheumatologist, then the rheumatologist is

there and the patient can have an immediate consultation instead of having to wait for another appointment," Chang explains.

"The idea is to get a comprehensive evaluation from the musculoskeletal and rheumatological perspectives, and the physical therapists who see our patients also are right on site," Chang adds. "So it's very easy for the physicians and therapists to communicate."

The center also makes referrals to other departments when necessary, such as to the facility's pain management program or to the physical therapy department for pool therapy.

Center offers exercise program

Soon the Arthritis Center will have a group exercise program for patients called PACE, meaning Persons with Arthritis Can Exercise. An aerobic exercise program for arthritis patients began in June.

Other available services include psychological evaluations on a consultation basis, massage therapy, acupuncture, and other complementary medical treatments.

3. Reimbursement.

Inpatient services and most traditional outpatient services, such as physical therapy and physician consultations, are paid for by Medicare, Medicaid, and private insurers just as they would be if the services were provided in any other type of rehab site.

"Complementary and alternative medicine services generally are not reimbursed and need to be paid out of pocket," Chang says.

4. Prevention services and public education.

"The public-health aspects of the center are very important," Chang says, adding that the chief executive officer of the Rehabilitation Institute of Chicago has a doctorate in public health and particularly wants to emphasize that aspect of the program.

"We are planning a series of community forums that will include screenings to educate the public about arthritis and what can be done about it," Chang says.

Also, there will be a patient education resource center that will feature Internet kiosks and CD-ROM players in the center's waiting area. These will give patients the opportunity to learn more about arthritis, medications, therapies, and surgeries.

"This will enhance the patient's understanding of their disease management, and this is all

in the spirit of trying to get them to be better self-managers of their disease process," Chang says.

Public education also will focus on prevention and highlight research showing that obesity is a significant risk factor for arthritis of the knee, Chang says.

"Since obesity is so prevalent in our population, we estimate that perhaps 20% to 30% of all knee osteoarthritis would go away if obesity was wiped out in this country," he says. "The other thing is that sports medicine people understand that there probably is an epidemic of knee injuries in adolescent females going on right now as a result of sports programs."

Adolescent girls have more lax ligament structure than boys, and the muscles around their knees are not as well developed, which makes them more prone to injury and therefore could place them at greater risk for osteoarthritis, Chang explains.

"Prevention is a new idea in arthritis treatment, but you don't have to look too hard to think of some strategies," Chang adds.

5. Research.

The Arthritis Center will continue in the rehab institute's tradition of being involved in research studies that could lead to better understandings of treatment, injury, and disease.

For example, the arthritis center was involved this year in a surveillance project that entailed a community survey of zip codes contiguous to the hospital's service area. The survey measured the prevalence of chronic joint symptoms in adults aged 45 or older and assessed their functional limitations. It also provided a needs assessment for those with arthritis, including a look at their need for education and clinical services.

"We contracted with Northern Illinois University, which has a large survey research program, and they conduct the annual Illinois Department of Public Health survey," Chang says. "We modeled a lot of our questions on that annual survey." ■

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Dog therapy means more than a pat on the head

Volunteer group does all the work

Pet therapy has become a popular volunteer service in various health care settings in recent years, but it mostly entails a friendly dog or cat and some petting time with patients. In Chicago, a non-profit organization called Chenny Troupe has taken pet therapy to a new level by making well-trained dogs available for patient rehabilitation therapy.

Recreational therapists match dogs and their volunteer owners with patients to create a weekly session in which patients work on their therapy exercises with the dogs.

"It's such a wonderful program, and every single week it's amazing because there's always a major outcome," says **Lisa Farmer**, CTRS, director of therapeutic recreation department at the Rehabilitation Institute of Chicago (RIC), which is one of the rehabilitation facilities that uses Chenny's free pet therapy services.

"Our program leader and volunteers work with the staff at each institution to make sure the exercises the patients are involved in help them meet therapeutic goals," says **Janet Rosen Eaton**, executive director of Chenny Troupe, which was founded 10 years ago.

For example, at one rehab facility in Chicago, a boy patient refused to walk and was unresponsive because of pain. It was only when the pet therapy dog and volunteer worked with the child that he began to exercise and walk. The boy's incentive was to play with the dog, Eaton recalls.

At RIC, the Chenny Troupe visits one evening a week with a group of eight or nine dogs and their owners. Recreational therapists match patients up with dogs according to each patient's goals and needs. For instance, a dog that likes to play catch will be matched with a patient who needs upper-extremity strengthening, Farmer explains.

If a patient is working on speech therapy goals, then the therapist might suggest that the patient call the dog or tell it to roll over or shake hands.

The sessions are designed to be successful, so even if the dog has difficulty understanding the patient's command, the dog's owner will be standing beside the patient giving the dog hand commands. This way, the dog will do exactly what the patient has commanded it to do, Eaton says.

"So it's a no-lose situation; they always succeed, and frustration is reduced," Eaton adds.

At the start of each pet therapy session at RIC, there is a general introduction made between patients and volunteers. Patients may talk about their own pets, and while introductions are being made, they can pet the dogs and get to know them. Then volunteers, dogs, and patients are paired into small groups because some dogs will work with more than one patient at a time, Farmer says.

Patients are screened according to their desire to work with the dogs and also for animal allergies. "It's an optional group," Farmer says. "We advertise the program around the hospital and talk with patients about it, but it's not mandatory."

RIC does not bill patients for the therapy time, but as it is considered a treatment program, the hours spent in pet therapy are entered in the patients' medical records, Farmer says.

RIC administrators were easily sold on the volunteer program when Chenny Troupe first presented it about eight years ago, Farmer says.

"We were very open to doing something like this, because we can always use animals in some way here, and this is very much therapy-oriented," Farmer says.

The Chenny Troupe has no difficulty finding rehab facilities and other organizations that would like to use pet therapy services, Eaton says. **(See story on Chenny Troupe's pet therapy services, below.)**

"We make sure a facility has a population that could benefit from the program, and since it's unique, we don't provide pet therapy for nursing homes, because there are other programs that can do that," Eaton adds. "We go into arenas where we can do what makes us unique." ■

Volunteers supply trained dogs to assist with rehab

Rigorous training yields top-notch canines

Dogs used by the Chenny Troupe of Chicago for animal-assisted therapy in rehab facilities and other health care settings could be described as some of the best-behaved and well-trained pets in the Midwest.

In order to pass the strenuous test, the dogs must follow human verbal and hand commands

to walk, heel, meet and greet, run through an agility course, stay in place for several minutes, and chase balls only when given permission to do so. All of this must be done without food rewards.

The dogs cannot jump up to give friendly greetings, and they must stay in place even when tempted to play with other dogs and toys around them. When they hear a loud noise, they cannot react, and if they fail even one minor part of the test, they are flunked and must take the entire test again.

This strenuous testing is a harder version of the Canine Good Citizenship test and the Therapy Dogs International test. The reason it's so difficult is that the dogs must be perfectly well-behaved in order to become pet therapists for emotionally and physically disabled individuals.

"Especially in physical therapy units, we have patients with catheters and fluid bags and people on gurneys and walkers and wheelchairs, and the dogs have to ignore all that," says **Judy Keitz**, a volunteer and member of the board of directors of the Chenny Troupe. Keitz also is president of Strategic Marketing Inc. in Chicago.

"The certification for our dogs is different, because if there's an emergency, we have to get the dog in a down-stay position immediately," Keitz adds.

Despite the stringent requirements and the high level of commitment required of the adult volunteers, who must commit to 100% attendance for programs at some facilities and at least 75% attendance at others, the program has had no difficulty in attracting volunteers and their pets. More than 300 dogs have passed the test since the nonprofit program was started in 1991, Keitz says.

"A lot of people and their dogs will have a 30% passing rate on the first try, and our tester who is a dog trainer will tell the owners what to work on with their dogs," Keitz says. "We say that any breed has the potential of doing it, but the more high-strung dogs don't usually make it."

Some of the breeds that have made the ranks of pet therapists include: Shi-Tzu, Great Dane, Golden Retriever, Labrador Retriever, Pembroke Welsh Corgi, Rottweiler, Airedale, and even one Terrier.

"We've never had a dog hurt or lunge at someone," says **Janet Rosen Eaton**, executive director of the Chenny Troupe.

While pet therapy sessions in nursing homes and hospice might involve a good-natured dog

visiting patients and being petted, the Chenny Troupe dogs are expected to work with patients in actual therapy. Also, the patients may be even more fragile, which is why the standards are so high for the dogs' behavior.

For example, the dogs may work with children who are burn victims. If the dog were to jump up spontaneously on the child, it could cause the child pain and injury. The Chenny dogs will never jump up in that way, Eaton explains.

Also, the dogs work in a group setting, so they must be able to do their job without being distracted by strangers, other dogs, unusual odors, loud noises, or medical equipment.

Chenny Troupe does not provide the actual dog training, but by requiring volunteers to pass the test, it encourages dog owners to train their dogs in obedience courses or on their own.

The organization provides pet therapy to several Chicago-area rehabilitation hospitals, as well as to other organizations, including adult and adolescent substance abuse treatment programs, Eaton says.

Children and youths especially respond well to the dog therapists. The contact helps them regain confidence and to improve their communication skills.

"One thing they learn is positive reinforcement and how gentle but firm commands work with the dogs," Eaton says. "So the kids learn how to be more productive in their human interactions."

With an annual budget of \$150,000, the program first was funded through the Junior League of Chicago and with private donations. Now the organization has a couple of fundraisers a year, including a pet fashion show, which supplement donations.

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- ❖ **Judy Keitz**, RIC Program Leader, Member of Board of Directors, Chenny Troupe; President, Strategic Marketing Inc., 1550 North Cleveland, Chicago, IL 60610. Telephone: (312) 280-1522.

Therapeutic recreation therapists and others across the country have contacted the Chenny Troupe to ask if they could set up models of their program in other cities, and the organization is considering doing so within the next five years, Keitz says.

Once a program is started, it doesn't take long to find volunteers and providers in and out of rehab who are interested in participating, Keitz adds.

As a volunteer, Keitz found that it meant as much to her as to the patients she and her dog assisted. "A lot of times there are those miracles that happen where a patient all of a sudden smiles for the first time or takes a step for the first time when seeing the dog," Keitz says. "When you're there, you forget everything else about your life, and you're totally focused on the patients for that hour and a half, and the dogs love it because they get 100% attention." ■

Give old muscle movements new options

Feldenkrais Method helps break bad habits

People usually try the Feldenkrais Method because they are experiencing pain and discomfort, says **Alice Brydges**, a certified movement therapist and Feldenkrais practitioner in San Francisco. That's how she was introduced to this therapy that harnesses the intelligence of the central nervous system through movement and guided attention.

As a dancer, she kept injuring herself over and over again. "I would recover from the injury for a while, but it always came back. I explored every therapy known to man, yet I couldn't stop hurting myself," says Brydges. Then she attended an Awareness Through Movement class that taught the Feldenkrais Method.

As she lay on the floor, following the instructor's verbal directions for movement — which included a lot of turning her head in one direction while looking in the opposite direction — she thought the exercises weren't doing much good. However, when she stood up, she felt like she was in a different person's body. The pain was gone and it never came back. The experience prompted her to train as a practitioner.

Now she works with people who are often as frustrated as she was. They are drawn to her Awareness Through Movement class or private sessions called Functional Integration for a variety of reasons. Women who've had mastectomies and are experiencing movement restrictions in their arms are interested in the Feldenkrais Method, as are professional athletes and dancers who want to learn how to move better. A bass guitar player who hurts his back each time he plays is trying to show his body new options for movement.

It's easy to develop habitual movement patterns. The Feldenkrais Method helps people become aware of habitual body positions and movements that can cause problems. Also, it helps them learn new ways of moving that might be more natural for them. "You move in a way that is familiar and you can't get out of that rut, but the nervous system is intelligent and it doesn't take a lot to learn something else," says Brydges. The Feldenkrais Method introduces so many options that the ruts begin to smooth out and the person is no longer committed to moving in only one way, she explains.

Non-intrusive therapy

During her classes, Brydges verbally guides participants through various choreographed movements. She does not demonstrate them, because the therapy is very individualized and people are to refrain from forcing their body into a position, which they might do if following the example of a teacher. For example, if the directions are to roll to the side, participants should only roll as far as is comfortable for them.

There are thousands of choreographed sequences in the Feldenkrais Method. Some are based on human developmental patterns, such as crawling, rolling, rolling to sit, and hand-eye coordination. "Most of the lessons are done lying down, and the reason for that is our anti-gravity muscles that hold us upright are very firmly entrenched in our nervous system and our movement pattern," says Brydges. Lying down takes the person out of the field of gravity, allowing other muscle groups to be accessed.

While classes are more affordable than a session with a practitioner, generally \$7 to \$10 versus \$60 to \$100, individual consultations are an option. During the session, a person would be asked to sit or lie on a low, wide padded table. The practitioner might observe the person performing specific

movements while lying down or standing up. The practitioner also might guide the person through movements, noting areas of strain and movement difficulty. The practitioner would then verbally guide the person through movement sequences that would indicate problem movements and give the person more options for movement, says Brydges.

Feldenkrais overcame his own disability

Moshe Feldenkrais developed the Feldenkrais Method in the early 1950s. After being disabled, he used his background in science to teach himself how to walk again by studying human movement. Now practitioners learn his methods to aid others who are injured, in chronic pain, or want to learn to move better.

The best way to find a practitioner is through the Feldenkrais Guild of North America. The Guild has a directory on its Web site (www.feldenkrais.com). If a practitioner is not available, instructional audiotapes can be used, says Brydges. (For a list of resources, see note below.) People often find it helpful to either repeat the movements at a class or on their own. It helps to remind the body of the new options for movement so it won't go back to old, familiar ways, says Brydges.

[Editor's note: A selection of audiotapes for beginners as well as people who have taken an Awareness Through Movement Class can be ordered through Feldenkrais Resources, 830 Bancroft Way, Suite 112, Berkeley, CA 94710. Telephone: (800) 765-1907. Fax: (510) 540-7683. E-mail: feldenres@aol.com. World Wide Web: www.feldenkrais-resources.com.] ■

Need More Information?

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Brydges has created a cassette tape series with an instructional booklet for breast cancer survivors. The series is called *Unbound! Gentle Movement Lessons for Breast Cancer Survivors*. It costs \$59.95 and is available on her Web site.

Increase awareness of SMA in August

Publicity may spur research, genetic testing

Spinal Muscular Atrophy (SMA), a disease of the anterior horn cells located in the spinal cord, is the No. 1 killer of children under the age of two. Yet, because it is one of the rare genetic diseases, not many people are aware of SMA, says **Audrey N. Lewis**, executive director of Families of Spinal Muscular Atrophy in Libertyville, IL. Families of SMA has named August as Spinal Muscular Atrophy Awareness Month.

SMA affects the voluntary muscles for activities such as walking and swallowing. One in every 40 people is a carrier, and one child in every 6,000 live births is affected. When people are aware of SMA, they can decide whether or not they want genetic testing prior to having children, says Lewis. Both parents must be carriers and each must pass the gene on to their child in order for the child to be affected by SMA. When both parents are carriers, the likelihood of having a child affected by SMA is 25%, or one in four children. Families of SMA recommends that couples who are carriers seek genetic counseling so they can understand the risk before having a child.

Another good reason for publicity is that people who are aware of SMA are more apt to contribute to the research being done to find a cure or treatment, says Lewis. Since the organization was founded, the research it has funded led to the mapping and cloning of the gene responsible for SMA, identification of the protein, development of carrier testing, and initiating the collaboration of scientists from around the world with an annual International SMA research group meeting. "The most exciting breakthrough is the finding that by replacing large amounts of the SMN2 protein in mice, spinal muscular atrophy could be prevented or reversed," says Lewis.

Types reveal prognosis

The severity of the disease depends on its type. Children with Type I (acute) SMA are never able to lift their heads. Also, feeding and swallowing may be extremely difficult and breathing can be labored because of reduced strength in the chest muscles. Repeated respiratory infections make

the prognosis for Type I SMA poor, and children who have the disease usually die within the first two years of life.

Children with Type II (chronic) SMA are able to sit unsupported but often need to be helped into a sitting position. If they walk, it is with the aid of bracing. Like children with Type I SMA, weakened chest muscles make them prone to respiratory infections such as pneumonia. Age of death varies greatly with Type II SMA; while some children die at age three, others survive into adulthood. Respiratory infection is usually the cause of death.

The prognosis is good for children with Type III SMA, and they often are functional for years before needing assistance. Type IV is adult-onset SMA with symptoms usually occurring after age 35.

For infants, children, and adults living with SMA Types I and II, each movement is an effort. "Those fortunate enough to have achieved some independence such as feeding themselves, writing, or playing wheelchair sports must also deal with the need for total personal care. They cannot dress, bathe, or toilet themselves or turn over and reposition themselves at night," says Lewis. Caregivers are often exhausted because they are awakened all night long to assist the child in the repositioning process.

Families with SMA kids need support

Relatives and friends should be encouraged to give parents a break by baby-sitting the SMA child when possible. It's also important that they refrain from critiquing the decisions parents make in the care of the child. "Families need support. Living with SMA is very different than reading about it," says Lewis.

Families who have a child diagnosed with SMA need to know their options and all the issues they may have to deal with. For example, most children

with Type I and II SMA develop scoliosis, a side-ways curvature of the spine. Although certain therapies do help, such as physical and respiratory therapy, parents must prepare for the financial impact SMA has. Most often children need an aide in order to go to school.

To promote education during Spinal Muscular Atrophy Awareness Month, Families of SMA has brochures, literature, and posters available. The organization also has a 10-minute educational video that can be borrowed. ■

Whatever you call them, wellness programs work

More employers reap benefits of prevention

Occupational health providers may grow weary of coming up with catchy new names for their walk-a-thons, bike-to-work weeks, Dump-Your-Plump months, and walk-at-lunch weeks, but the effort is worthwhile. The programs work, says **D.W. Edington**, MD, director of the Health Management Research Center (HMRC) at the University of Michigan in Ann Arbor.

These week-long and month-long programs reflect an employer's commitment to workplace wellness programs, and it's a commitment that has increasingly become a year-round phenomenon for thousands of employers, Edington says. He presented advice on the worth of such wellness programs at the research center's recent Wellness in the Workplace Conference in Ann Arbor.

Spend money now to save it later

"Corporations now see health management programs as the only long-term alternative to the continuing escalation of medical care costs. Nearly 60% of all companies and 95% of large companies have programs designed to encourage individuals to take some responsibility for their own health," Edington says.

"There is greater return from investment in preventing healthy people from slipping into poor health behaviors than by trying to make chronically sick people well. Individuals benefit in terms of less pain and suffering and a higher quality of life. The corporation benefits in terms

Need More Information?

For more information about SMA, or for materials to support educational efforts during Spinal Muscular Atrophy Awareness Month, contact:

📧 **Audrey N. Lewis**, Executive Director, Families of Spinal Muscular Atrophy, P.O. Box 196, Libertyville, IL. Telephone: (800) 886-1762. Fax: (847) 367-7623. E-mail: sma@interaccess.com. World Wide Web: www.fsma.org.

of less medical care costs and greater productivity," he notes.

Employers were first introduced to the concept of investing in health promotion programs in the 1970s. By the 1980s, employers were spending \$5 per employee per year on workplace wellness programs. Today they're shelling out \$60 per employee for year-round programs that range from smoking cessation programs to lessons in handling stress.

The cost: 1% to 2% of typical medical care costs. Workplace wellness programs have caught on. They are more than a trend, more than an experimental program of employers who know they can trim health care costs and improve productivity by providing an environment where employees remain healthy. Employees like the programs because exercising, eating right, and relaxing make them feel better. Employers like such programs because happier, healthier employees are more productive and cost less.

HMRC research shows that workplace wellness programs save employers \$80 to \$225 per employee per year in medical care costs and an equal amount in productivity gains.

"Work-site health management programs are part of the new way to do health care in America," Edington says. "Everyone benefits, and it is truly one of the classic win-win situations for all the stakeholders." ■

Group studies unresolved back pain after surgery

25% of patients continue to experience pain

Back pain can persist even after successful spine surgery, leaving the physician debating whether to proceed with reoperation or spinal cord stimulation. To help make the decision easier, the National Spine Network (NSN), an association of the country's leading comprehensive spine centers, has embarked on a prospective, randomized, multicenter clinical trial comparing the outcomes of spinal cord stimulation with repeat spine surgery for patients suffering from failed back surgery syndrome.

The study's launch was announced recently at the American Academy of Orthopedic Surgeons meeting. Approximately 200,000 Americans

annually undergo an initial spine surgery for the treatment of chronic low back pain, according to a 1998 survey of spine surgeons commissioned by Medtronic. The same research indicates that about 25% of these patients continue to experience unresolved pain after surgery. And, despite a second procedure to relieve the pain, more than 13,000 patients still suffer from unresolved pain.

"This landmark NSN study promises to yield the data we need to make the best treatment recommendations for patients with low back pain that remains unresolved after a successful spine surgery," said **Bruce Fredrickson, MD**, principal investigator for the study and an orthopedic surgeon specializing in spine procedures at the State University of New York (SUNY) Upstate Medical University in Syracuse.

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Editorial Questions

Questions or comments?
Call Kevin New, (404) 262-5467.

“For the first time, we are undertaking research of sufficient scope to predict which patients are most likely to benefit from additional surgery and which patients are better candidates for spinal cord stimulation,” says Fredrickson.

The study also seeks to determine which treatment option — spinal cord stimulation or repeat spine surgery — provides reduced pain, greater functional status, improved quality of life, and reduced disability to patients with unresolved low back pain.

Network seeks to improve spine care

“The National Spine Network advocates an interdisciplinary approach to the treatment of spine disorders, including chronic low back pain,” said **Harry Freedman**, executive director of the Marietta, GA-based NSN. “Our involvement in this study demonstrates the NSN’s commitment to improve the cost-effectiveness, consistency, and quality of spine care.”

Eleven NSN member institutions are participating in the study: Washington University Medical Center in St. Louis; Emory Spine Center in Decatur, GA; Hospital for Joint Diseases in New York; Hospital for Special Surgery in New York; Nebraska Spine Center in Omaha; Swedish Medical Center - Providence Campus in Seattle; Rush Presbyterian-St.Luke’s Medical Center in Chicago; SUNY Upstate Medical Center in Syracuse; Texas Back Institute in Plano; University Hospitals of Cleveland; and University of Iowa Medical Center in Iowa City.

The study calls for the enrollment of 150 patients by early 2003. Once enrolled, each patient will be followed for 24 months with follow-up at three, six, 12, 18, and 24 months. The final results of the study are expected to be published by 2005.

Candidates for the study must meet all entry criteria, including previous back surgery more than a year prior to enrollment, failure of alternative treatment measures such as medical or physical therapies, disabling pain that has limited their social and vocational activities, age 20 or older, no medical contraindication to surgery (including pregnancy), and clearance from a clinical psychiatrist if indicated.

Spinal cord stimulation and spine surgery can significantly reduce chronic low back pain of neuropathic etiology. Spinal cord stimulation works by blocking pain signals from reaching the brain, where they would be perceived as pain.

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Spine surgery works by either decompressing pinched nerves that cause pain or connecting two or more bones in the spine.

As with any treatment, side effects can occur. Because spinal cord stimulation systems are surgically placed, infections are possible. Potential complications from spinal cord stimulation may include undesirable changes in stimulation, lead migration, and loss of pain-relieving effects in some patients.

Risks of surgery include excessive bleeding and an adverse reaction to anesthesia. Because spine surgery involves the nervous system, nerve damage is another risk. Both spinal cord stimulation and reoperation are standard medical procedures used to treat chronic pain.

The NSN is a nonprofit organization comprising 28 independent centers of excellence for spine care.

Health care providers who think a patient may be eligible to enroll in this clinical trial can call (319) 335-8408 or visit www.NSNOnline.org/FBSS for more information. ■

American Health Consultants Education and Training Fax-back Survey

We would like to learn more about training and education needs for you and your staff. Please circle the number corresponding to your level of interest in the following topics:

	No Interest	1	2	3	4	5		No Interest	1	2	3	4	5
HIPAA privacy rules	1	2	3	4	5		Palliative care	1	2	3	4	5	
Stark II	1	2	3	4	5		End-of-life care	1	2	3	4	5	
EMTALA	1	2	3	4	5		Assisted suicide	1	2	3	4	5	
Aftermath of ergonomics	1	2	3	4	5		Genetic testing	1	2	3	4	5	
OSHA compliance	1	2	3	4	5		Organizational ethics	1	2	3	4	5	
Post-exposure prophylaxis	1	2	3	4	5		Human research protection	1	2	3	4	5	
Influenza update	1	2	3	4	5		Informed consent documentation	1	2	3	4	5	
Antibiotic resistance	1	2	3	4	5		New accreditation standards	1	2	3	4	5	
Adverse drug reactions	1	2	3	4	5		Observation units (23-hour care or recovery beds)	1	2	3	4	5	
Drug interactions	1	2	3	4	5		ED diversion	1	2	3	4	5	
Medication errors	1	2	3	4	5		Avoiding lawsuits: What to say when something goes wrong	1	2	3	4	5	
Herb-drug interactions	1	2	3	4	5		Improving documentation for nurses and physicians	1	2	3	4	5	
Nosocomial infections	1	2	3	4	5		Nursing shortage	1	2	3	4	5	
Patient falls	1	2	3	4	5		Bioterrorism	1	2	3	4	5	
Basic information for frontline workers	1	2	3	4	5		Disaster planning and mass casualties	1	2	3	4	5	
Needlesticks	1	2	3	4	5		Safety and security	1	2	3	4	5	
Latex sensitivity	1	2	3	4	5								
TB compliance	1	2	3	4	5								
Restraints and the violent patient	1	2	3	4	5								
Pain management	1	2	3	4	5								

What training format is preferred for you and your staff? Rate the following methods using the scale below:

	Least Preferred					Most Preferred
On-site speakers	1	2	3	4	5	
Travel off-site to live conferences	1	2	3	4	5	
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Outside-sponsored videoconferences	1	2	3	4	5	
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