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Special Report: Managing RSD

Do you groan when you get a reflex sympathetic dystrophy case?

Here's help demystifying the syndrome's diagnosis and treatment

A 22-year-old woman admitted to Bethesda Naval Hospital in Maryland with a bleeding disorder had contracted reflex sympathetic dystrophy syndrome or complex regional pain syndrome (RSD/CRPS) at age 17, after undergoing routine surgery. The pain and frustration led to a depression that caused her to attempt suicide. And the issues raised by her RSD left nurses and physicians at Bethesda Naval scrambling for advice on how to treat her bleeding disorder.

Americans With Disabilities Act turns 10

Former President George Bush signed the Americans With Disabilities Act into law on July 26, 1990. More than 10 years later — at the start of a new millennium full of technological advances — there is evidence that the quality of life has improved for the 54 million Americans with disabilities. Yet, there is just as much evidence to indicate that much more work needs to be done.

Inside, you will find the latest results of an ongoing survey that tracks the degree to which disabled Americans experience full and equal participation in the workplace and other aspects of life. You will also find useful tips from an integrated disability management team with a high degree of success in getting its clients back to work, as well as a special report on reflex sympathetic dystrophy syndrome (RSD) — one of the most challenging disabilities facing workers' comp and disability case managers. ■

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She's not alone. The Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) in Haddonfield, NJ, estimates that as many as 5% of all injuries or surgeries result in RSD, a disorder marked by burning pain, swelling, and motor and sensory disturbances, associated with sympathetic nervous system dysfunction. "It's a hidden disability with very powerful psychiatric overtones. There are times when you want to take your life," confides **Wilson H. Hulley**, a member of the executive staff of the President's Committee on Employment of People with Disabilities in Washington, DC, and a special assistant to both the Bush and Clinton administrations on disability issues. Hulley also lives with RSD. He was contacted by a patient advocate at Bethesda Naval when the young woman was admitted to the hospital. "It was an emergency call. The woman was clotting at the same time she was having a very painful RSD episode. I've been working with her, but she's in the later stages of Stage III RSD and it's making her life miserable," he says. **(For information on the staging of RSD, see p. 7.)**

"When I was first diagnosed, I met with a neurologist at Johns Hopkins in Baltimore who told me he could help me for two years and then I would probably commit suicide like the majority of his other RSD patients," says Hulley. "I never went back to him again."

Intense emotional strain

It shouldn't surprise case managers that RSD patients experience emotional and psychological disturbances, notes **Anthony F. Kirkpatrick, MD, PhD**, associate professor of medicine at the University of South Florida in Tampa and editor of the RSD/CRPS clinical practice guidelines. "It's not only the excruciating intensity but also the bizarre nature of the pain caused by RSD that leads to these disturbances," he says. "Some RSD patients describe their pain as feeling as if bugs are crawling all over their bodies, and as the pain spreads from one region to another, patients comment that it's as if a 'demon' is moving around inside them."

Kirkpatrick emphasizes that the unique nature of RSD pain and its psychosocial components are well-described in the literature. "The pain of RSD is the most excruciating form of pain. It has been studied and compared to the pain of cancer, arthritis, and childbirth and it always comes out as one of the most intense types of pain imaginable."

He adds that studies designed to determine whether RSD patients had a pre-existing psychiatric condition prior to developing RSD or a predisposition for psychiatric disturbances have been negative. "These studies simply haven't panned out. It's simply the nature of this pain, not underlying psychiatric issues, that causes emotional and psychiatric problems in RSD patients."

The psychological impact of the pain and disability caused by RSD must be addressed adequately throughout treatment before the primary diagnosis shifts from RSD to a psychiatric diagnosis, cautions **Janet M. Frontera, RN, BSN, CCM, A-CCC**, medical consultant for the Pittsburgh claim office of CIGNA IntegratedCare. "Too often, the treating physician keeps the patient on such high doses of pain medication that the patient simply sits at home watching television and moving very little. Patients become so frustrated and depressed that, if nothing is done to address the psychiatric component of this diagnosis, the depression moves from a comorbid condition to becoming the primary disability claim."

Clinicians who specialize in pain management often fight case managers to provide adequate psychiatric treatment for their patients. "We commonly run into this issue with case managers," says **Srinivasa N. Raja, MD**, with the department of anesthesiology, division of pain medicine at Johns Hopkins Hospital in Baltimore. "This condition often affects young people who have been very active. RSD impacts their lifestyle and hits them hard financially; therefore, we observe a high percentage of depression in these patients."

Raja urges case managers to seek psychotherapy for RSD patients designed to help them cope with their disability and motivate them to facilitate functional improvement. "It's common that RSD patients start out very optimistic," he notes.

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“As their condition fails to resolve, the physical problems are less important and the psychological aspects of this condition worsen. The degree of anger, frustration, and depression must be adequately addressed as part of the overall management of the syndrome.”

Diagnosing RSD requires a careful and thorough medical history. A diagnosis of RSD/CRPS requires a history of trauma to the area associated with pain that is disproportionate to the inciting event, plus one or more of the following symptoms:

- abnormal function of the sympathetic nervous system;
- swelling;
- movement disorder;
- changes in tissue growth, either dystrophy or atrophy.

A survey of more than 1,300 RSD sufferers found that 33.5% of respondents experienced RSD following surgery. Another 19.8% experienced the first symptoms of RSD following a fall.

Other triggering events reported by respondents include:

- Nearly 19% of respondents experienced their first symptoms following a fracture.
- Roughly 15% of respondents experienced their first symptoms following a sprain.
- Roughly 14% of respondents experienced their first RSD symptoms following a crush injury.
- Just over 12% experienced their first RSD symptoms following a contusion.

A diagnosis of RSD/CRPS is often made when there is an absence of all other possible pathology that might explain the pain and symptoms of the patient. “RSD is an end-of-the-spectrum diagnosis,” says Frontera. “By the time a diagnosis of RSD is made, the treating physician has usually looked at and treated many other conditions. This is often a ‘when all else fails’ diagnosis.”

When case managers see a diagnosis of RSD, or CRPS, as it is becoming more commonly known, they should review the patient’s medical record for evidence that all other possible causes of the pain have been ruled out. “Nerve conduction studies and selective diagnostic nerve blocks are very useful as diagnostic tools to help pinpoint the source and cause of a patient’s pain,” notes Raja, adding that a significant number of patients who are referred to him with a diagnosis of RSD have been misdiagnosed. (Other useful diagnostic tools are described in the recently published RSD/CRPS guidelines available on the RSDSA Web site at www.rsd.org.)

Who gets reflex sympathetic dystrophy?

A survey of more than 1,300 individuals with reflex sympathetic dystrophy (RSD) conducted by the Reflex Sympathetic Dystrophy Association of America in Haddonfield, NJ, reveals the following about the demographics of this disabling syndrome:

- 77.9% of respondents were women.
- 94.4% of respondents were white.
- The average age of respondents at the onset of RSD was 36.8 years.
- 92.8% of respondents had no family history of RSD.
- The average time span between the onset of symptoms and diagnosis of RSD was .87 years. ■

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“If the patient has not undergone a thorough neurological examination, order one immediately,” he urges. “A few years ago, I had a patient referred to me with a diagnosis of RSD who had pain that had spread from the hand to the shoulder region. We subsequently worked up the patient’s cervical spine and found a protruding disc that was pressing on the spinal cord and causing the pain.”

Why not the best?

Kirkpatrick urges that case managers refer RSD patients to a university medical center for initial diagnosis and treatment. “When care is initiated at a major teaching center, it gives the patient a jump start,” he notes. “University-affiliated hospitals have clinicians who are current on research and development issues and are more likely to be able to properly do a sympathetic block of the lower extremities. An inexperienced clinician may do an epidural block instead of a selective nerve block and the results would not be useful for determining the cause of the pain — it’s not cost-effective.”

In addition to being a good diagnostic tool, nerve blocks are also useful for promoting rehabilitation, agree Raja and Kirkpatrick. “Early intervention with physical therapy is essential for maintaining or restoring functionality in RSD patients,” says Raja. “Many patients discontinue

physical therapy due to the pain caused when the affected limb is moved. Physical therapy scheduled immediately following a selective nerve block can greatly increase a patient's range of motion by increasing the patient's ability to tolerate pain," he notes, adding that physical therapy should be limited to improving range of movement and increasing muscle strength in RSD patients.

Patients with RSD may experience some or all of the following six clinical features of RSD/CRPS described in the clinical practice guidelines, which were developed by a panel of 13 RSD specialists and published by RSDSA. (For more information on the guidelines, see p. 5.)

1. Pain. Patients with RSD/CRPS suffer from pain and mobility problems out of proportion to those expected from the initial injury. The first and primary complaint occurring in one or more extremities is described as severe, constant, burning, and/or deep aching pain. All tactile stimulation of the skin, even the wearing of clothes, may be perceived as painful.

"We had a woman contact us because an airline refused to let her fly because she couldn't tolerate a shoe on her foot," says **Jim Broatch**, MSW, executive director of RSDSA. "Eventually, the airline did allow her to fly rather than face a lawsuit."

Other RSDSA members have been unable to return to work because of workplace dress codes, he adds. "You can't go back to work if wearing clothes is too painful. Employers have to be very flexible about everything, including dress codes, for an employee with RSD to successfully return to work. A case manager could help by explaining the situation to the employer and discussing options such as the possibility of the employee wearing shorts to work."

In addition, Frontera and Raja both note that it's important to negotiate part-time work for RSD patients. "Too many patients try to return to work full-time and end up regressing," says Raja. "Few patients with RSD can return to their original workload without backsliding."

Frontera always encourages patients to first try part-time work before jumping back to their original workload, especially when they have psychological issues. "The stress of returning to work with the added issue of dealing with pain often causes patients who have been out on disability to relapse. It's much better for patients to return part-time and gradually increase their hours, as

they feel able." (For further tips on effective disability case management, see p. 14.)

2. Skin changes. The skin over the affected area may appear shiny, dry, or scaly. Hair may initially grow coarse and then thin. Nails in the affected extremity may be more brittle, grow faster, and then slower. The patient may perceive sensations of warmth or coolness in the affected limb without even touching it. The skin may show increased sweating or increased chilling.

Changes in skin color range from a white mottled appearance to a red or blue appearance. Hulley experienced his first symptoms of RSD after orthopedic surgery to repair a fractured bone in his foot. "My foot grew swollen and my entire leg turned the colors of the rainbow," he recalls. "The surgeon was positive I had acquired RSD, but it was another four months from the original swelling and discoloration that the diagnosis was confirmed."

3. Swelling. Pitting or hard edema is usually diffuse and localized to the painful and tender region. If the edema is sharply demarcated on the surface of the skin along a line, it is almost proof that the patient has RSD/CRPS.

4. Movement disorder. Patients with RSD/CRPS have difficulty moving because they hurt when they move. In addition, there seems to be a direct inhibitory effect of RSD/CRPS on muscle contraction. Decreased mobilization of extremities can lead to wasting of muscles.

"There isn't an RN or PT who won't tell you that atrophy can do more damage than anything else psychologically or physically," says Hulley.

"It's essential to initiate activity in the affected extremity and not allow it to just hang there and do nothing," says Frontera. "Physical therapy can keep the affected extremity as functional as possible and prevent or reduce atrophy. Therapy also can keep the patient from developing a disability mindset."

5. Spreading symptoms. Initially, RSD/CRPS symptoms are localized to the site of the original, triggering injury. With time, the pain and symptoms tend to become more diffuse. The RSDSA survey found that more than 71% of RSD sufferers cannot identify a reason for the spread of their symptoms. In addition, survey respondents indicated that the average time from initial symptoms to spread to other regions of the body was 12.8 months.

*'Case managers
can be a godsend
to a patient.'*

The disorder typically starts in an extremity. Three patterns of spreading symptoms are described in the literature. **(Suggested readings on this and other related topics are listed in the box on p. 6.)**

Those patterns of spread are:

- continuity type spread where the symptoms spread upward from the initial site, for example from the hand to the shoulder;
- mirror-image type spread where the symptoms spread to the opposite limb;
- independent type spread where the symptoms spread to a separate, distant region of the body.

6. Bone changes. X-rays may show wasting of bone, or patchy osteoporosis. A bone scan may show increased or decreased uptake of radioactive substance (technecium 99m) in bones after intravenous injection.

Let's talk

Of course, once a diagnosis of RSD has been confirmed, it takes a team approach to effectively coordinate the necessary care. "At a bare minimum, following an initial evaluation and treatment at a university center, a primary care physician must work with a mental health provider — either a psychologist or a psychiatrist, as necessary," says Kirkpatrick. "In an ideal situation, the patient lives close enough to a major medical center that an RSD specialist could be added to the patient's team."

The four treatment goals outlined in the RSDSA clinical practice guidelines are:

- educate about therapeutic goals;
- encourage normal use of the limb with physical therapy;
- minimize pain;
- determine the contribution of the sympathetic nervous system to the patient's pain.

Case managers must play an active role on the treatment team of the RSD patient, says Raja. "Case managers and physicians working together can help the patient set realistic treatment goals. Too often the patient has unrealistic expectations and those complicate the entire situation. We are not talking about a 'cure' when we work with RSD patients but rather improvements in function and quality of life. It helps if the physician and the case manager can sit down together and talk — too often valuable time is lost in the communication process."

Kirkpatrick stresses that treatment flows more smoothly when all interested parties are kept

fully informed about the patient's treatment protocol and progress. "Many of these patients are involved in litigation. There are attorneys and case managers involved as well as physicians and therapists," he notes. He suggests that a patient update report be shared with the patient and include the following five areas:

- procedures performed;
- medications prescribed;
- physical and occupational therapy notes;
- psychosocial issues;
- new laboratory tests or consults.

Hulley agrees that the patient should play an important role in the communication process. "Every time I see one of my physicians, I ask for a copy of the report and fax it to each of my other treating physicians," he notes, adding that currently his own treatment team includes a pain management specialist, a psychiatrist, a physical therapist, and an orthopedic surgeon. "My dentist is also an RSD specialist who understands my special pain management needs."

He urges case managers to advocate for RSD patients and support all areas of their lives. "RSD can tear families apart. It puts tremendous strain on marriages," he says. "Case managers can be a godsend to a patient." ■

Clinical guidelines keep treatment cost-effective

They also empower RSD/CRPS patients

Reflex sympathetic dystrophy syndrome (RSD) or chronic regional pain syndrome (CRPS) is a complex chronic pain syndrome that recently became much easier for patients and their case managers to cope with, thanks to clinical practice guidelines published by the Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA) in Haddonfield, NJ.

"The guidelines provide a basis for determining which care is essential care, which care is optional care, and which care is contraindicated," says **Anthony F. Kirkpatrick**, MD, PhD, associate professor of medicine at the University of South Florida in Tampa and editor of the RSD/CRPS clinical practice guidelines. "They minimize the need for patients to seek multiple second opinions

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Try these RSD resources

The following resources may help you improve the quality of life and functional capacity of your clients with reflex sympathetic dystrophy syndrome (RSD). However, RSD remains a complex and controversial diagnosis some clinicians refer to as the “diagnosis of last resort.” Case managers will have to help patients sort through the information in these resources and find the treatment options most applicable to their own situation.

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- Alpher EJ, Kirsch DL. A patient with traumatic brain injury and full body reflex sympathetic dystrophy treated with cranial electro-therapy stimulation. *AJPM* 1998; 8:124-128.
- Janig W, Stanton-Hicks M, eds. Reflex sympathetic dystrophy: A reappraisal. *Progress in Pain Research and Management* Vol.6. Seattle: IASP Press. 1996.
- Kirkpatrick A, Derasari M. Transdermal clonidine: Treating reflex sympathetic dystrophy. *Regional Anesthesia* 1993; 18:140-141.
- Kirsch DL, Smith RB. The use of cranial electrotherapy stimulation in the management of chronic pain: A review. *NeuroRehabilitation* 2000; 14:85-94.
- Law J, Kirkpatrick A. Update: Spinal cord stimulation. *Am J Pain Manag* 1992; 2:34-42.
- Olcott C, Lorne G, et al. Reflex sympathetic dystrophy — the surgeon’s role in management. *J Vasc Surg* 1991; 14:488-495.
- Quin H, Abram S. Neural blockade for diagnosis and prognosis. *Anesthesiology* 1997; 86:216-241.
- Raja S. Nerve blocks in the evaluation of chronic pain: A plea for caution in their use and interpretation. *Anesthesiology* 1997; 86:4-6.
- Schwartzman RJ. New treatments for reflex sympathetic dystrophy. *N Engl J Med* 2000; 343:684-686.
- Stanton-Hicks M, Baron R, et al. Consensus report: complex regional pain syndromes: Guidelines for therapy. *Clin J Pain* 1998; 14:155-156. ■

and help focus the process of diagnosing and treating RSD in a cost-effective and appropriate manner. The guidelines also help both the patient and the case manager evaluate the quality of the care the patient is receiving.”

Too often, Kirkpatrick notes, time and resources are wasted in the treatment of RSD patients. “The guidelines were written by a committee of 13 RSD specialists, all dedicated to rehabilitating RSD patients in the shortest possible time with the most appropriate resources,” he says. “I deal with case managers and attorneys all the time. I see a lot of money and time wasted in the treatment of this condition. The guidelines help prevent that waste of time and money by presenting a logical, cost-effective approach to the treatment of RSD.”

Kirkpatrick urges case managers to make copies of the guidelines available to their patients. “The guidelines are written in a manner that is easily understood by most patients,” he notes. “They help patients provide informed consent for their own care and provide a strong basis for making treatment decisions.”

Reading the guidelines helps patients understand their condition and therefore gain control of their pain, he adds. “We have received feedback from patients that confirms that reading the guidelines helps them make informed decisions about their care and gain control of their pain. That sense of control also helps them cope better with their pain — the pain is the same, but it doesn’t bother them as much.”

The clinical practice guidelines are available on the RSDSA Web site at www.rsds.org. ■

Out-of-pocket expense can be devastating

Financial burden adds insult to injury

Wilson H. Hulley, a member of the executive staff of the President’s Committee on Employment of People with Disabilities in Washington, DC, and a special assistant to both the Bush and Clinton administrations on disability issues, spends \$1,600 a month for a custom pain preparation, and that is only one of the monthly out-of-pocket expenses he bears as he tries to cope with the crippling pain of reflex sympathetic

dystrophy syndrome (RSD).

“My original injury was work-related. I work for the President’s Committee on Employment of People with Disabilities and I’m still trying to get workers’ comp to pay for the \$1,600 a month,” he says, adding that he’s

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already spent \$18,000 of his own money for the custom preparation.

“Unfortunately, the philosophy of the workers’ comp and the Social Security Administration in Baltimore seems too often to be, ‘If we just hold off, maybe the patient will just go away or die, and we won’t have to worry about it.’ I’m fortunate that I had money in the bank when this began. I don’t have any left.”

At different points since his diagnosis, Hulley has been evaluated by three separate workers’ comp case managers who all filed reports attesting to his disability. “They all tried to advocate for me. And, they were sometimes treated quite poorly by others in the system. These case managers can be a

pain in the side of the doctor and can be a gift to the patient trying to sort through the confusion of medical and employment benefits.”

Hulley and the Reflex Sympathetic Dystrophy Association of America (RSDSA) in Haddonfield, NJ, are waiting for a ruling from the Social Security Administration’s Office of Disability that would help people like Hulley with severe RSD receive more timely benefits to help them pay for the treatments they need if they can’t work.

A survey conducted by the RSDSA found that an overwhelming majority of RSD patients can’t work full-time. Of more than 1,300 RSD patients surveyed:

- More than 38% of respondents report being unemployed because of RSD.
- Only 17.4% of respondents report being employed full-time.
- Roughly 5% of respondents report being employed part-time due to RSD.
- Just over 21% report being employed but not

Three stages of RSD

The course of reflex sympathetic dystrophy syndrome/complex regional pain syndrome (RSD/CRPS) is so unpredictable that many clinicians argue staging of RSD is not particularly necessary or helpful in its treatment. However, the Reflex Sympathetic Dystrophy Syndrome Association of America in Haddonfield, NJ, does identify the three stages of RSD described below in the recently released second edition of its *Reflex Sympathetic Dystrophy/ Complex Regional Pain Syndrome (RSD/CRPS) Clinical Practice Guidelines*. (For more discussion of the clinical features of RSD/CRPS, see the cover story.)

Stage One

- onset of severe pain limited to the site of injury;
- localized swelling;
- muscle cramps;
- stiffness and limited mobility;
- warm, red, dry skin which may change to cyanotic, or blue, in appearance and become cold and sweaty;
- increased sweating.

In mild cases, this stage lasts a few weeks, then subsides spontaneously or responds

rapidly to treatment.

Stage Two

- pain becomes even more severe and more diffuse;
- swelling tends to spread and it may change from a soft to hard type;
- hair may become coarse, then scant;
- nails may grow faster, then grow slower and become brittle, cracked, and heavily grooved;
- spotty wasting of bone occurs early but may become more severe and diffuse;
- muscle wasting begins.

Stage I and Stage II symptoms begin to appear within a year of the triggering event. Some of the early symptoms of Stage I and Stage II may fade as the disease progresses to Stage III.

Stage Three

- marked wasting of tissue, eventually becoming irreversible;
- increasingly intractable pain that may involve the entire limb.

A small percentage of patients develop generalized RSD affecting the entire body. Some patients never progress to Stage III. ■

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currently working because of RSD.

In addition, roughly 50% of respondents report receiving no compensation or disability payments to help with medical and living expenses with another 32.4% reporting that they have an application for compensation or disability now pending. ■

Survey results paint a portrait of pain

Ask them about their pain and patients with Reflex sympathetic dystrophy (RSD) paint a devastating portrait of the type of pain that keeps them lying flat on their backs far too much of the time and interferes with their quality of life. Here's what a survey of more than 1,300 RSD patients, conducted by the Reflex Sympathetic Dystrophy Association of America in Haddonfield, NJ, revealed about the pain associated with RSD:

- More than 70% of respondents report suffering from "constant" pain.
- Roughly 17% of respondents report suffering from "nearly constant" pain.
- Seventy-four percent of respondents report having to stop daily activities "frequently" due to pain.
- Twenty-three percent of respondents report having to stop daily activities "occasionally" due to pain.
- More than 84% of respondents report that pain prevents them from sleeping.
- Eighty-six percent of respondents report that pain awakens them from sleep.
- More than 30% of respondents report that pain interferes with their marriage and family life "all of the time" and another 28.9% report that pain interferes with this area of their lives "most of the time."
- More than 35% of respondents report that pain interferes with social activities and friendships "all of the time" and another 30.5% report that pain interferes with this area of their lives "most of the time."
- Roughly 63% of respondents report that pain interferes with employment "all of the time" and another 18.2% report that pain interferes with this area of their lives "most of the time."
- Roughly 50% of respondents report that pain

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interferes with housework and chores "all of the time" and another 32.3% report that pain interferes with this area of their lives "most of the time."

- Forty-seven percent of respondents report that pain interferes with hobbies and recreation "all of the time" and 33% report that pain interferes with this area of their lives "most of the time."
- Thirty-three percent of respondents report that pain interferes with sexual activity "all of the time" and another 23.2% report that pain interferes with this area of their lives "most of the time."

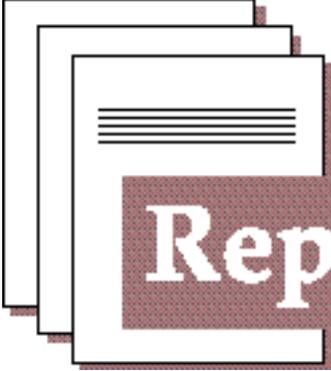
When asked the effect of various positions or activities on their pain, respondents report the following:

- Roughly 47% report lying down decreases their pain and only 15.8% report that lying down increases their pain.
- Less than 3% report that standing decreases their pain and more than 70% report that standing increases their pain.
- Roughly 35% report that sitting decreases their pain and roughly 45% report that sitting increases their pain.
- Roughly 6% report that movement decreases their pain and more than 79% report that movement increases their pain.
- Roughly 7% report that exercise decreases their pain and more than 85% report that exercise increases their pain.
- Less than 5% report that work decreases their pain and 79% report that work increases their pain.
- Roughly 58% report that medicine decreases their pain, and another 39.9% report that medicine has no effect on their pain. Only 2.6% report that medicine decreases their pain. ■

What spells relief for RSD sufferers?

People with moderate to severe reflex sympathetic dystrophy syndrome (RSD) often take a veritable cocktail of prescription drugs in an attempt to manage the pain, depression, and anxiety caused by this disabling condition. When those drugs fail, patients turn to a wide range of alternative therapies in their constant search for pain relief.

(Continued on page 13)



Reports From the Field™

Disease Management

Therapy prevents platelet depletion in hep C patients

Nearly 25% of the estimated 4 million Americans with hepatitis C either cannot start or must discontinue treatment with the current standard of care due to low platelet levels. Now, researchers believe that these patients can safely begin or continue treatment at a full dosage and without interruption when they are treated with the platelet growth factor Interleukin-11, according to a small study presented at the recent American Association for the Study of Liver Diseases annual meeting in Dallas.

The study was conducted at Georgetown University Hospital in Washington, DC. Researchers used the platelet growth factor in four patients with chronic hepatitis C to prevent low platelet levels, thereby allowing completion of full-dose therapy with Interferon and Ribavirin.

“In medicine, we are always looking for new ways to use existing therapies,” notes **Vinood Rustgi**, MD, medical director of liver transplantation at Georgetown University Hospital and lead investigator of the study. “These preliminary findings show that Interleukin-11’s ability to avoid low platelet counts and prevent stable platelet counts from diving in chemotherapy patients may also enable more hepatitis C patients to start treatment and maintain it safely.”

Of the four patients in the study, two received Interleukin-11 to correct therapy-induced low platelet levels. In the remaining two patients, Interleukin-11 was started before antiviral therapy to prevent further decreases in platelet counts. All study participants responded favorably to Interleukin-11 treatment and experienced improved platelet levels.

Interleukin-11 is currently approved by the U.S. Food and Drug Administration, for patients undergoing myelosuppressive chemotherapy at high risk of severely low platelet levels. It is a platelet growth factor that stimulates the bone marrow to make normal platelets, helping to maintain platelet counts, which may minimize the possibility of having to change myelosuppressive drug dosing or timing.

In randomized studies, most adverse events associated with the drug were mild to moderate. The most common included peripheral edema, dyspnea, tachycardia, and conjunctival redness. These side effects were reversible after discontinuation of dosing. ▼

Drug delays onset of multiple sclerosis

An ongoing study of Interferon beta-1a indicates that the therapy significantly reduces the rate at which individuals at high risk for multiple sclerosis (MS) develop clinically definite multiple sclerosis (CDMS). Researchers found that the therapy, manufactured under the brand name Avonex by Biogen in Cambridge, MA, reduced the rate of development of CDMS by

44% over treatment with placebo.

In addition, Avonex showed a highly significant positive impact in reducing the rate at which patients developed brain abnormalities, or lesions, visible on MRI scans. These findings indicate that the increase in brain MRI lesion volume was 91% lower in patients treated with Avonex compared to the placebo group.

The CHAMPS (Controlled High Risk Subjects Avonex Multiple Sclerosis Prevention Study) trial was originally designed to last three years, but was stopped in 2000 following a planned interim efficacy analysis. An independent data monitoring committee determined that the benefit of Avonex treatment was significant enough to halt the trial in order to expedite the filing for registration for this important indication.

The randomized, double-blind, placebo controlled trial was conducted at 50 clinical centers in the United States and Canada and involved more than 383 patients who were determined to have a high probability of developing CDMS based on brain MRI changes and clinical events consistent with MS. Study participants received either 30 mcg of Avonex or placebo, injected intramuscularly once a week for up to three years.

Additional information on Avonex is available on the Biogen Web site at www.biogen.com. ▼

One-week therapy heals *H. pylori* ulcers

Esomeprazole, the first proton pump inhibitor (PPI) developed as an isomer, effectively eradicates *Helicobacter pylori* when combined with two antibiotics and heals duodenal ulcers without the need for follow-up PPI monotherapy, reducing the treatment period from four weeks to one for patients with *H. pylori*-associated duodenal ulcers, according to data presented at the European Helicobacter Pylori Study Group workshop held recently in Rome.

Results of the two multi-center studies demonstrate that 20 mg of esomeprazole twice daily in seven-day triple therapy with the standard antibiotics amoxicillin and clarithromycin twice daily, effectively eradicates *H. pylori* in 90% of patients. In addition, researchers found that use of seven-day esomeprazole triple therapy heals associated duodenal ulcers in more than 90% of patients, eliminating the need for three-

week follow-up monotherapy.

Esomeprazole is manufactured under the brand name Nexium by AstraZeneca in Wilmington, DE. For more information on esomeprazole, visit the Nexium interactive Web site at www.nexiumpressooffice.com. ▼

Study compares two Alzheimer's drugs

A head-to-head study of two Alzheimer's drugs found that donepezil hydrochloride was much better tolerated in patients with mild to moderate Alzheimer's disease than rivastigmine tartrate, according to researchers who presented their findings at a recent scientific meeting in Munich.

The study used manufacturers' recommended dosages to compare the two current Alzheimer's treatment options. The multinational, head-to-head, random, double-blind, open-label study was designed to compare the tolerability and ease of use of donepezil hydrochloride to rivastigmine tartrate in 111 patients with mild to moderate Alzheimer's disease.

The two treatment groups had similar improvements from baseline in Alzheimer's Disease Assessment Scale-cognitive subscale scores throughout the 12-week treatment period. ADAS-cog is a clinically validated measure of cognitive function. Testing was administered by independent raters who were blinded to the study medication. Findings include:

- 41.8% of patients in the rivastigmine tartrate group reported nausea compared with 10.7% in the donepezil hydrochloride group.
- 23.6% of patients in the rivastigmine tartrate group reported vomiting compared with 7.1% in the donepezil hydrochloride group.
- 87.5% of patients were able to remain at the maximum daily dose of donepezil hydrochloride compared with 47.3% of patients who were able to remain on the maximum daily dose of rivastigmine tartrate.

Physicians were surveyed about their overall satisfaction with study medication for each patient. Physicians reported being "very satisfied" with the study medication for 46.4% of patients treated with donepezil hydrochloride compared to 18.9% of patients treated with rivastigmine tartrate.

“Despite the often devastating nature of the disease, tolerability is still very important to patients with Alzheimer’s disease,” says **David Wilkinson**, MD, director of the Memory Assessment and Research Centre at Moorgreen Hospital in Southampton, England, an investigator in the study. “Patients tend to be elderly and often have other medical conditions that can make treating Alzheimer’s disease more complex. It is therefore important to treat patients with medications that are well-tolerated and easy to use, such as donepezil hydrochloride.” ▼

Beta blocker reduces heart failure deaths

The beta blocking agent carvedilol reduces the risk of death or hospitalization due to heart failure by nearly a third in patients with advanced stages of the disease who were already taking an ACE (angiotensin-converting enzyme) inhibitor, according to new data presented at the recent 73rd annual Scientific Sessions of the American Heart Association in New Orleans.

The COPERNICUS (Carvedilol Prospective Randomized Cumulative Survival) study was conducted in more than 300 medical centers in 21 countries and included more than 2,200 patients with advanced heart failure who had symptoms at rest or minimal exertion, but not requiring intensive care unit care or intravenous treatments to support their heart’s function. In the controlled trial, 50% of patients received carvedilol and 50% received placebo in addition to their current heart failure medications which included ACE inhibitors, diuretics, and digoxin. Patients were evaluated for an average of 10.5 months.

Findings include:

- Carvedilol decreased mortality by 35%.
- Carvedilol reduced all-cause mortality or heart failure hospitalizations by 31%.
- Carvedilol reduced all-cause mortality or cardiovascular hospitalizations by 27%.
- Carvedilol reduced all-cause mortality or hospitalizations for any reason by 24%.

Approved by the Food and Drug Administration, in 1997, carvedilol is manufactured under the brand name Coreg by SmithKline Beecham in Philadelphia and Roche Pharmaceuticals in Nutley, NJ. ▼

New drug reduces diabetic cell decline in type 2 patients

A new study finds that pioglitazone hydrochloride, the most recent addition to the thiazolidinedione class of medications, significantly reduces insulin resistance and reduces the decline of pancreatic cell function in type 2 diabetes patients who receive sulfonylurea therapy, according to data presented at the recent 36th annual European Association for the Study of Diabetes meeting in Jerusalem.

The 16-week, placebo-controlled study of 521 patients found that pioglitazone hydrochloride significantly reduced insulin resistance and improved beta cell function when added to the treatment regimen of patients on sulfonylurea therapy at low (15 mg) and intermediate (30 mg) doses. Adding pioglitazone hydrochloride to sulfonylurea therapy resulted in a 30% reduction in insulin resistance and a 38% improvement in beta cell function compared to baseline. ▼

Behavioral health

Race affects psychiatric drug efficacy

Certain medications may be more successful than others for treating African-Americans with mental illness, according to a study conducted by researchers at the University of South Carolina in Columbia. Researchers concluded that when African-Americans diagnosed with manic-depressive disorder, depression, schizophrenia, and anxiety disorder are prescribed Prolixin or Zyprexa, they have more relief from symptoms associated with those illnesses and improved functioning than with other prescription medications.

The University of South Carolina study looked into the effect of antipsychotic medications over a 12-month period on 60 African-Americans diagnosed with schizophrenia and related disorders.

Findings include:

- The type of antipsychotic medication used in the care of African-Americans with schizophrenia is an important factor in the overall outcome and success of treatment.

- In African-Americans, a lower metabolism by a specific enzyme may account for differences in the way antidepressant and antipsychotic medications are absorbed by the body and metabolized.

- There is an increased chance of central nervous system side effects and toxicity if dosage is not adjusted appropriately among African-Americans due to significant difference in red blood cell to plasma lithium ratios.

- In addition to the use of Prolixin and Zyprexa, no other medication, community-based outpatient service, or daily treatment and support service accounts for a significant impact on clinical outcomes.

- Among the new antipsychotic medicines currently in use, Prolixin and Zyprexa, when taken by African-Americans, were the best predictors of improvement in psychotic symptoms and functioning.

“This new data provides further evidence that medications, even in the same classification, are not interchangeable and individuals may respond to them differently, says **Rusty Selix**, executive director of the Mental Health Association in Sacramento, CA. “Even though atypical antipsychotics, such as Prolixin and Zyprexa, are more expensive in the short-term, long-term cost savings are significant because individuals are less likely to be institutionalized, to be on welfare, or become incarcerated and more likely to lead productive lives,” he notes, adding that there is a twofold increase in an individual’s ability to return to the workplace while under treatment with atypical antipsychotics. ■



New leukemia drug approved for relapse patients

Trisenox (arsenic trioxide) injection, manufactured by Cell Therapeutics in Seattle, recently received approval from the Food and Drug Administration to treat patients with a severe form of leukemia whose disease has recurred or

who have failed to respond to standard therapy.

A pivotal trial involving 40 patients with relapsed/refractory acute promyelocytic leukemia (APL) unresponsive to standard therapies was conducted at nine institutions. Of those 40 patients treated with Trisenox, 70% achieved a complete remission, with the majority achieving molecular eradication of the genetic abnormality associated with APL. Complete remission was achieved on average within two months after initiation of Trisenox.

“We are impressed at both the high rate of complete remission and the relapse-free survival in this high-risk population of APL patients whose previous treatment failed to eradicate their disease,” says **Steven Soignet**, MD, investigator in the Developmental Chemotherapy Service at Memorial Sloan-Kettering Cancer Center in New York City.

Trisenox is administered intravenously in two phases. Induction therapy consisting of daily injections of 0.15 mg/kg until the bone marrow is cleared of leukemic cells, for up to a maximum of 60 days. This is followed by consolidation therapy using the same dose for 25 days beginning three weeks after bone marrow remission is evident.

For information on Trisenox availability, call toll-free (888) 305-2289, or visit the Cell Therapeutics Web site at www.cticseattle.com. ▼

Once-daily migraine treatment approved

The Food and Drug Administration recently approved Depakote ER (divalproex sodium extended-release tablets), a once-daily formulation for the prevention of migraine headaches in adults by Abbott Laboratories in Abbott Park, IL.

In a 16-week, multi-center, double-blind, placebo-controlled study of 107 migraine sufferers, patients receiving Depakote had a mean four-week migraine headache rate of 3.5 compared to a mean rate of 5.7 for the placebo group. In a similarly designed second trial of 176 patients, Depakote-treated patients had a mean four-week migraine rate of 3.2 compared to a mean rate of 4.5 for the placebo group.

For more information on Depakote, visit the Abbott Web site at www.abbott.com. ■

(Continued from page 8)

Since contracting RSD, **Wilson H. Hulley**, a member of the executive staff of the President's Committee on Employment of People with Disabilities in Washington, DC, and a special

**Special Report:
Managing RSD**

assistant to both the Bush and Clinton administrations on disability issues, has been prescribed a wide range of

medications, including Prozac, Catapres, Kolopin, Risperdal, Levo-Dromoran, C-Dextromethorphan, Effexor, and Fentanyl patches.

"When I was first diagnosed, I used duralgesic patches for four years. After three and a half years, I began to have bladder and bowel problems and I took myself off the patches," notes Hulley. "In addition to the bladder and bowel problems, I was constantly drugged, which increased my inability to function at work and at home."

Now Hulley, like many other RSD sufferers, uses a combination of other treatments, resorting only occasionally to pain medications. Among treatments Hulley believes have given him relief from his constant pain are whole-body acupuncture, which provides six to seven hours of relief, and a cranial electrotherapy stimulation (CES) unit called Alpha-Stim manufactured by Electromedical Products International (EPI) in Mineral Wells, TX. Hulley says the small cigarette pack-sized unit, which applies a low-level electric current through the head via ear clip electrodes, brings him several hours of relief.

"After using the CES unit for about 20 minutes, the patient becomes more relaxed and more alert," explains **Daniel Kirsch**, PhD, a neurobiologist and chairman of the board of EPI. "There is no such thing as pain without mood swings. The biggest challenge in pain management is helping people function better in society. When people are more relaxed, they function better and their pain doesn't hurt as much — the pain is present but more manageable."

"RSD can be reviewed as the sympathetic nervous system stuck on overdrive," says Kirsch. "It's easier to activate a physiological function than to suppress it. We think CES activates the vagus nerve, the leading parasympathetic nerve, and that activation of the parasympathetic system helps offset the overactivation of the sympathetic nervous system."

The Alpha-Stim unit Hulley uses sells for about

\$450 and comes with a five-year warranty, says Kirsch. "That's a lot cheaper than the prescription drugs commonly used by chronic pain patients."

Searching for relief

RSD patients like Hulley often try multiple therapies to achieve pain relief. A survey of more than 1,300 RSD patients conducted by the Reflex Sympathetic Dystrophy Association of America in Haddonfield, NJ, found that those pain relief strategies include:

- Seventy-three percent of respondents have tried heat treatments with 23% reporting moderate relief and roughly 6% reporting excellent relief. About 16% reported that heat treatments worsened their pain.

- Eighty-nine percent of respondents have tried physical therapy with roughly 22% reporting moderate relief and about 9% reporting excellent relief. About 24% reported that physical therapy worsened their pain. However, roughly 10% of those patients who received physical therapy reported permanent pain relief following treatment.

- Sixty-three percent of respondents have tried bed rest. Roughly 35% reported moderate relief and about 5% reported excellent relief. About 7% reported that bed rest worsened their pain.

- Nearly 74% of respondents have tried elevation of the affected extremity with roughly 30% reporting moderate relief and about 6% reporting excellent relief. About 6% reported that elevation worsened their pain.

- Thirteen percent of respondents have tried acupuncture with roughly 15% reporting moderate relief and about 9% reporting excellent relief. About 17% reported that acupuncture worsened their pain.

- Roughly 18% have tried chiropractic care with roughly 16% reporting moderate relief and 7.3% reporting excellent relief. Nearly 20% reported that chiropractic care worsened their pain.

- Roughly 16% have tried traction with 16.8% reporting moderate relief and less than 3% reporting excellent relief. More than 32% reported that traction worsened their pain.

- Nearly 30% have tried biofeedback with 20.7% reporting moderate relief and 6% reporting excellent relief.

- Twenty-nine percent have tried psychotherapy with 23.5% reporting moderate relief and 7.2% reporting excellent relief. Nearly 11% of those patients who received psychotherapy reported permanent relief following treatment.

- Nearly 69% have tried a TENS (transcutaneous electrical nerve stimulation) unit with 23% reporting moderate relief and roughly 5% reporting excellent relief. Roughly 16% of patients using TENS units reported that their pain worsened after treatment.

- More than 73% have tried nerve blocks with roughly 30% reporting moderate relief and less than 4% reporting excellent relief.

- About 17% have tried sympathectomies with about 23% reporting moderate relief and less than 2% reporting excellent relief. Of those who received moderate to excellent relief, 24% reported the relief was permanent.

- Roughly 42% have tried pain clinics with 26.5% reporting moderate relief and less than 1% reporting excellent relief.

In addition to pain management, Hulley finds that his service dog greatly improves his quality of life. "She picks up things that I drop when I can't bend over, and when I'm in a crowd she protects my legs, because it hurts to have them touched," he says.

(Editor's note: Several books and a video are available that explain the science behind the Alpha-Stim system. For ordering information and descriptions of these resources, visit the Electromedical Products International Web site at www.epii.com.) ■

Workers' Comp/Disability Management

Disabled Americans have made great strides

But 10 years after passage of ADA, gaps remain

Case managers, attorneys, and other patient advocates, armed with the Americans with Disabilities Act (ADA), have helped disabled Americans make progress re-entering the workplace and integrating into their communities. Yet, 10 years after the ADA became law, persistent gaps remain in participation levels between people with disabilities and other Americans in employment, income, education, socializing, religious and political participation, as well as access to health care and transportation, according to a survey conducted by the National Organization

on Disability (NOD) in Washington, DC.

The *2000 NOD/Harris Survey of Americans With Disabilities* measures participation gaps in 10 key measures of quality of life between people with disabilities and those without. Survey results are based on responses from 997 people with disabilities and 953 people without disabilities. The survey identifies the following gaps:

- Only 32% of disabled people of working age (18-64) work full- or part-time, compared to 81% of the nondisabled population, a gap of 49%. More than two-thirds of those disabled people not employed say they would prefer to be working. However, the employment gap narrows in younger people with disabilities. Among disabled people between the ages of 18 and 29, 57% of those who are able to are working compared to 72% of their non-disabled peers, a gap of only 15%.

- People with disabilities are almost three times as likely as people without disabilities to live in households with total incomes of \$15,000 or less — 29% compared to 10%, a gap of 19%.

- People with disabilities are less likely to be registered to vote than people without disabilities — 62% compared to 78%, a gap of 16%.

- People with disabilities are almost three times as likely as people without disabilities to say that inadequate transportation is a problem — 30% compared to 10%, a gap of 20%.

- People with disabilities are less likely to graduate from high school than people without disabilities — 22% compared to 9%, a gap of 13%.

- People with disabilities are less likely to socialize with close friends, relatives, or neighbors than people without disabilities — 70% compared to 85%, a gap of 15%.

- People with disabilities are less likely to attend religious services — 47% compared to 65%, a gap of 18%.

- People with disabilities are more likely to face barriers to health care services — 19% compared to 6%, a gap of 13%.

- People with disabilities are less likely to express high satisfaction with their quality of life — 33% compared to 67%, a gap of 34%.

- People with disabilities are less likely to go out to a restaurant at least once a week — 40% compared to 59%, a gap of 19%.

Narrowing the gap

The good news is that the gap between people with disabilities and those without seems to be narrowing in some cases. NOD has conducted its

survey for many key indicators. Comparing the results of the 2000 survey to those of the 1998 and 1994 surveys reveals the following trends:

- The education gap between disabled Americans and nondisabled Americans was 13% in 2000 compared to 11% in 1998 and 12% in 1994.
- The socialization gap between disabled Americans and nondisabled Americans was 15% in both 2000 and 1998 compared to 18% in 1994.
- The religious attendance gap was 18% in 2000 compared to 3% in 1998 and 10% in 1994.
- The entertainment/dining out gap was 19% in 2000 compared to 27% in 1998 and 21% in 1994.
- The annual income gap was 19% in 2000 compared to 22% in 1998 and 1994.
- The access-to-health-care gap was 13% in 2000 compared to 10% in 1998 and 5% 1994.

NOD says that there has been continuous progress in all 10 of the key indicators and speculates that the indicators which appear to show a negative trend, for example, the 2% rise in the education gap between 1998 and 2000, may be explained by the increasing number of severely disabled Americans. As proof, NOD notes that the number of disabled Americans who express satisfaction with their quality of life has risen steadily from 20% in 1994 to 28% in 1998 and 34% in 2000. In addition, 41% of disabled Americans surveyed in 2000 report expect their quality of life to improve in the next four years.

“We take heart from the many hopeful signs in this survey, indicating the success of the ADA,” says **Alan A. Reich**, president of NOD. “Among young people with and without disabilities, age 18-29, the employment gap is only 25% and narrowing. Large numbers of people with disabilities reported that conditions had improved for them during the past four years. This reflects intensive efforts by the disability community, employers, and community leaders, as well as advances in technology, and greater accessibility. The ADA is having an impact. We must all work to close the remaining gaps. This is ADA’s agenda in the new millennium.”

The executive summary of the *2000 NOD/Harris survey of Americans with Disabilities* is available online at www.nod.org. The 125-page report including the 35-page survey questionnaire showing tabulated responses is available from NOD for a cost of \$95. You may order online, or by calling NOD at (202) 293-5960. ■

Team approach eases employees back to work

It also helps if you know how to ‘schmooze’

It’s not impossible to get a physician’s attention when you have no financial carrots to dangle, but it’s as close to impossible as it comes. Disability case management teams are often the best chance an employer has to get a valued employee back to work after illness or injury, but the job of those team members is unique in the world of case management.

“I’m not in a position to approve payment for the physician’s services or any other medical services or medical equipment, which makes my job challenging. The health care side calls all of the monetary shots,” explains **Janet M. Frontera**, RN, BSN, CCM, A-CCC, medical consultant for the Pittsburgh claim office of CIGNA IntegratedCare. “A workers’ comp case manager might be able to pick up the phone and arrange an MRI for a patient, or authorize six more physical therapy visits; I can’t.”

What Frontera does, with the help of the other members of the disability case management team at CIGNA, is develop an organized approach to managing each disability claim with a goal of returning the claimant to full- or part-time employment whenever possible.

The minute a disability claim comes into CIGNA IntegratedCare, a case manager is assigned to review it. If the claim seems straightforward, for example, a short-term disability due to a fracture, the case manager may be the only one to work on it. However, if the diagnosis or prognosis is unclear, the case manager calls in the other members of the disability case management team — the occupational consultant and the medical consultant.

“I have to know when to call in our consultants and also how to take their expert opinions back to my desk and use them to make a claim decision,” explains **Kristen L. Stagliano**, BA, case manager for long-term disability at the Pittsburgh claims office of CIGNA IntegratedCare. “In addition to the occupational consultant and the medical consultant, we have economic and Social Security consultants on staff to help claimants with terminal or long-term progressive diagnoses file for benefits and plan for their financial future.”

Case managers begin by contacting the

claimant and the physician to assess the claimant's functional capacity. "If the claimant is preparing to return to work, or seems motivated to return to work, I bring in the occupational consultant to work with the claimant and the employer on any return-to-work issues, such as modified duty or workplace modifications. If the claimant has a comorbid psychiatric condition, or the medical situation is unclear for other reasons, I call in the medical consultant."

Good customer service

After the consultants have been called in and done their initial evaluation of the claimant, the team sits down together to set goals for the claimant. "This approach not only helps us work through the claim efficiently, but it also gives the claimant several other contacts here at CIGNA. If the claimant has a pressing question and the case manager is not available, there are two other professionals familiar with the claim that the claimant can talk to," Stagliano says. "It's wonderful for customer service. Claimants don't have to constantly retell their stories."

The team approach works, say Stagliano and Frontera, because each team member brings a unique perspective and set of skills. "The case managers have ownership of the claims and are experts on understanding the policies and issuing benefits," Frontera says. "However, the early intervention of the nurse and occupational consultants are essential to getting claimants back to work."

For both the occupational consultant and the medical consultant, success depends on their ability to build a rapport with the interested parties. "My first contact, after reviewing the file and the medical record, is with the claimant," says **Shelley S. Mayhak**, MEd, CRC, CDMS, an occupational consultant for CIGNA IntegratedCare in the Pittsburgh claims office. "I introduce myself and my role. I'm very honest right up front that my goal is to get people back to work. The claimant's reaction to that statement helps me get a perception of their own goals. Most people want to go back to work."

Mayhak describes herself as a "cheerleader." She explains, "If I have information in the medical record that the claimant has the ability to return to work, I ask for permission to contact the employer about return-to-work issues. And when I get on the phone with the employer I start selling. I tell

them, 'This employee is really anxious to return to work.' The earlier on in the claimant's disability, the more potential there is for a successful return to work, and the less likely that the employer will have found a replacement."

If a claimant seems reluctant or unsure about returning to work, Mayhak explains that CIGNA provides some financial incentives in most of its disability contracts. "Essentially, I explain to them that they may be able to return to work and still qualify for a partial or full benefit. It's less scary to the claimant if we keep the claim open just in case they return to work and have a relapse."

"I try not to be judgmental," she adds. "Sometimes, you catch someone on a bad day. Maybe the claimant is a cancer patient who has just received chemotherapy. I try to feed them some work incentives and suggest they take time to think about it. Often, I call back in a few weeks and the claimant is much more motivated to return to work. Sometimes, the claimant calls me a week later because they are feeling better and can't wait to get back to work."

Mayhak uses the rapport she develops with claimants to encourage them to keep in contact with their supervisors and co-workers. "Often, the claimant is uncomfortable or reluctant to contact their supervisor, especially if they've been out for awhile. I spend time encouraging the claimant to go ahead and make that call."

Of course, sometimes the claimant's injury or illness means that a return to work requires special accommodations. "It's important to have as detailed a job description as you can get from the employer. You have to know exactly what tasks are necessary and work with the employer, the claimant, and the physician to determine whether or not the claimant can do the required work," says Mayhak. "The job description may call for a medium work level requiring lifting of 20 to 50 pounds. The physician may say the person can't do that job because they aren't able to lift. But it may be possible for a co-worker to do the lifting."

In addition, Mayhak often calls in a physical or occupational therapist to conduct an on-site job analysis. "The local treating therapist is the best person for the job because they are best qualified to know the claimant's abilities and limitations."

In many cases, very inexpensive workplace modifications can solve a return-to-work problem. "For example, for an individual with a herniated disc in her neck who works in a position

***'Most people
want to go
back to work.'***

where she spends a good deal of time on the phone, something as simple as a headset, which the employer may already have available, may be all it takes for the physician to release the claimant and make it possible for the claimant to do her job.”

Picking up the tab

At other times, CIGNA finds that getting the employee back to work requires reaching into its own wallet. “We had a young man who was injured and ended up in a wheelchair. The health plan provided a wheelchair, but he hadn’t yet developed enough upper body strength to lift the chair in and out of the trunk of his car and it was preventing him from returning to work,” recalls Frontera. “I asked the health plan for a second wheelchair, but was told that one chair was a necessity and two was a convenience she couldn’t fund. After a meeting with team members and discussion with the employer, it was decided we would fund the cost of a second chair for this patient, who was very motivated to return to work.”

Frontera has the unenviable task of developing relationships with physicians in order to get the claimant the care necessary to facilitate that return to work, which is the team’s ultimate goal. It’s not easy to gain a physician’s cooperation when you have no financial clout to get his or her attention. Here are some strategies Frontera says have worked well for her:

- **Know the file inside and out.** “I need to know every provider the claimant is seeing and review each provider’s progress notes,” she says. “I may find that the claimant is seeing a therapist for depression and the treating physician doesn’t know it. I may find that claimant has a comorbid condition that the treating physician is unaware of and not treating.”

- **Do your research.** “I often use the Internet to help me gain a better understanding of a patient’s condition,” Frontera says. “I have my favorite Web sites that have been recommended by our physicians as providing reliable medical information on new drugs and new therapies. If the claimant’s condition is unfamiliar to me, I’ll get online and gather the latest information available before contacting the treating physician.”

- **Contact the claimant first.** “Without the cooperation of the claimant, my task becomes even more challenging,” Frontera notes. “Generally, the case manager tells the claimant

that I will be calling, to smooth the way for me. I contact the claimant to develop a clear picture of the situation — the claimant’s ‘spin’ — before contacting the treating physician. And, from the very first contact, I establish a relationship with the claimant so we can talk about return to work and we work together to set realistic goals for that return to work.”

Frontera conducts a medical interview with the claimant over the telephone. She gathers information on the patient’s medical history, current medications, current therapies, and activities of daily living, as well as the claimant’s personal perception of disability and expectations for return to work.

She may also enlist the claimant’s help making contact with the treating physician. “I’ll tell the claimant that I’ve faxed their physician a list of questions that I need answered in order to get them their benefits and ask the claimant to give the physician a call.”

- **Set up an appointment with the physician.** Cold-calling a physician is never a good idea, cautions Frontera. “The physician has so many patients to treat, they might not even be able to recall the claimant you’re calling about. Set up an appointment time with the physician’s office staff and fax a list of questions ahead,” she suggests.

By taking those two steps, not only will the physician have the claimant’s chart close at hand and be ready to answer your questions, but you will also have shown respect for the physician’s time. “Physicians appreciate it if you’re organized and get straight to the point. Their time is very limited. You’ve proven yourself by being prepared. You get on the phone, you ask your questions, and you get off. You’ve been quick and to the point. It helps get a plan in place that you and the physician agree on. If you want the physician to talk to you, make it as easy as possible,” Frontera suggests.

Flex-time

And, be flexible with your time, she urges. “Making yourself available to the physician is essential. If you’re on the East Coast setting up an appointment with a physician on the West Coast, suggest that you catch them before they start their office hours. Try catching physicians on their lunch hour, or offer to stay late and talk to them.”

- **Show your appreciation.** “The first thing I do when I get on the phone is thank the physician in advance for speaking with me. And, I never get off

the phone without thanking the physician again and asking for permission to speak with him or her again as the disability claim continues,” Frontera says, adding, “I rely on knowledge and experience as a nurse to help me develop an effective working relationship with the treating provider, which usually results in positive outcomes for everyone involved, especially the claimant. Still sometimes it’s necessary to ‘schmooze’ a bit to gain a physician’s cooperation.”

Another trick Frontera finds useful is to ask for the physician’s help understanding the claimant’s medical condition. “It’s not because I don’t understand the claimant’s condition, it’s just a useful tool for developing a dialog with the physician,” she says. “It puts the physician in the position of using their medical knowledge to clarify things for me, and as the conversation develops we discuss the effectiveness of current treatment, functionality of the claimant, and prognosis for return to work. Most physicians open up and share tons of information.”

- **Be helpful.** Many times a claimant is being seen by more than one provider and none of the providers is aware of the others, notes Frontera. “I’ll let the primary physicians know there is another physician involved and try to facilitate communication between them.”

Patients may confide in you

At other times, the claimant may confide information to Frontera that the physician is unaware of, she notes. Frontera remembers one claimant with uncontrolled hypertension who, according to her file, was receiving multiple prescriptions to treat her hypertension, yet still not able to bring her blood pressure down to an acceptable level.

“I asked her to be honest with me and she confided that she hadn’t had any of the prescriptions filled, because she couldn’t afford them. She hadn’t told her physician because she was embarrassed.”

Frontera asked the claimant for permission to discuss the matter with her physician. “I asked her physician whether it was possible for him to give her free samples. He did, and her blood pressure finally was controlled. I don’t think the nurse should come between the physician and the patient – but it is appropriate to help the physician and the patient develop an open dialogue.”

At other times, the claimant may have an adverse reaction to a medication the physician has prescribed that the physician is unaware of,

notes Frontera. “I’ll call the physician and say that the claimant is complaining that the medication is causing nausea, and ask what alternatives are available. In addition, I do encourage claimants to contact their physicians directly to discuss their medical needs and often help them formulate questions to ask.”

It also helps if you can lift part of the administrative burden of the claim off the physician’s shoulders. “I always tell the physician that there’s no need to fill out a form or send me a letter about the claimant now that we’ve talked. I offer to do the necessary documentation.”

In addition, Frontera finds that claimants don’t always communicate to their physicians what their job involves. “Sometimes, the physician hasn’t released the claimant back to work simply because he doesn’t know what the job requires. I tell the doctor, or the occupational consultant tells the doctor, what the job requires. Then we [say], ‘Don’t tell me what the patient can’t do, tell me what he can do.’ If the patient is unable to return to work, I ask the physician what test results or positive exam findings he has that indicate this patient is incapable of doing his job.”

- **Bring out the big guns.** If a treating physician is particularly uncooperative, Frontera asks one of the physician advisors she works with at CIGNA to make a call to the treating physician. “That physician-to-physician call is definitely the ‘hardball’ approach. It also often makes the difference with a claim. Generally by the end of these calls we have a better understanding of the claimant’s medical conditions, the physician’s treatment plan and the prognosis for return to work.”

The case manager remains the person who keeps all the pieces of the claim together from the time CIGNA receives it until the claim is either denied or closed. “We have [a procedure] that case staffing and then the occupational consultant, or the medical consultant, whoever is working with the claim, reports back to me verbally with updates as necessary,” says Stagliano.

“When I first started at CIGNA, we didn’t use the team approach. I’ve witnessed how much smoother the entire claims process is now. The occupational and medical consultants have expertise that I don’t have. And I have an understanding of the benefits that they don’t have, I definitely think the team approach benefits the claimant and the employer.” ■

Online help for epilepsy issues

Internet center addresses health/quality of life

The Epilepsy Foundation in Washington, DC, recently launched the Online Center for Clinical Care, an Internet-based resource for health care providers working with individuals with epilepsy.

The center is the product of epilepsy experts on the foundation's professional advisory board. It is organized into the following five categories:

- assessment;
- planning;
- treatment;
- populations;
- resources.

"The Online Center recognizes that epilepsy is more than treating seizures, and the disorder has far-reaching effects on every facet of a person's life," says **Tracy A. Glauser, MD**, associate professor of pediatrics and neurology and director of the Children's Comprehensive Epilepsy Program at Cincinnati Children's Hospital Medical Center, who chaired the development group. "The site consolidates information on issues ranging from alternative therapies to matter of education, employment and family planning. We are unaware of any similar online epilepsy information resource created for allied health professionals."

The Online Center can be accessed at www.epilepsyfoundation.org/clinicalcare/. ■

Experts agree e-health holds great promise

Unfortunately, survey finds public uneasy

Case managers are beginning to use the Internet for online research, communicating with patients and providers, and monitoring the health of chronically ill patients. As a nation, we seem to agree that the Internet holds great promise for streamlining health care delivery and improving health care access.

E-health experts from the nation's leading

academic medical centers, the federal government and e-Health companies gathered recently in Washington, DC, to debate the Internet's potential for improving health care delivery in the United States at a meeting of the Academic Medicine and Managed Care Forum, an alliance of health care organizations. Unfortunately, a newly released national survey indicates that despite the Internet's promise, it may be years before the public is ready to embrace e-Health applications.

"Facilitating public access to high-quality scientific information can play a very important role in improving health care for those who can get that information, and for those whose doctors can use it," notes **Donald A. B. Lindberg, MD**, director of the National Library of

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Editorial Questions

Questions or comments? Call **Lee Reinauer** at (404) 262-5460.

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Medicine at the National Institutes of Health in Bethesda, MD. However, at the same time, Lindberg cautions that even with improvements in information networking, many medical and practical problems make it difficult in the short term to achieve “true equal access by all to the best care.” (For further information about e-Health, see *Case Management Advisor*, May 2000, pp. 73-81; and Oct. 2000, pp. 161-167.)

E-Health experts present at the meeting shared their views on how the Internet is changing the face of health care delivery and its potential for future applications. Among those applications cited are:

- elimination of administrative hassles associated with health benefits;
- improved physician-patient communication via Internet;
- increased connectivity and seamless care delivery between providers and health plans due to electronic patient records.

In doc we trust

Yet, one of the greatest barriers to the future growth of e-Health applications may not be the need for further technical refinements, but rather the need to overcome consumer reluctance, according to the results of new Gallup survey commissioned by MedicAlert Foundation in Turlock, CA.

The Gallup survey is one of the first to check the pulse of the general public — not just Internet users — and underscores the grave concerns of many Americans about online privacy violations.

Findings of the national survey include:

- Only 7% of respondents report they are very willing to store or transmit personal health information on the Internet.
- Only 8% report they feel a Web site could be trusted with such information.
- Ninety percent report they would trust their physician to keep their personal health information private and secure.
- Sixty-six percent report they would trust a hospital to keep their personal health information private and secure.
- Forty-two percent report they would trust an insurance company to keep their personal health information private and secure.
- Thirty-five percent report they would trust a managed care company to keep their personal health information private and secure. ■

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CE objectives

After reading this issue, continuing education participants will be able to:

1. Identify clinical, legal, legislative, regulatory, financial, and social issues relevant to case management.
2. Explain how those issues affect case managers and clients.
3. Describe practical ways to solve problems that case managers encounter in their daily case management activities. ■

Resource Bank™

A monthly compilation of news you can use from *Case Management Advisor*

WEB ALERT



Web site helps seniors navigate Medicare

The Washington, DC-based American Association of Homes and Services for the Aging's Center for Medicare Education has developed a Web site to assist care managers who help seniors navigate the increasingly confusing world of Medicare.

The new site at www.medicareed.org includes resources, technical assistance papers, information on upcoming events, ideas, and case studies on education efforts nationwide.

The goal of the center is to build an information infrastructure to support the many different kinds of professionals who find themselves counseling beneficiaries about their choices in the Medicare program and how to navigate the health care maze. ▼

Web site empowers cancer patients and survivors

The American Cancer Society in Atlanta recently solidified an agreement with NexCura, an integrated e-company in Seattle, to "embed" NexCura's Cancer Profiler interactive health care decision-support tools on the society's Web site at www.cancer.org. The agreement allows visitors to www.cancer.org access to Cancer Profilers for breast, colorectal, prostate, and several other cancers.

"The agreement between the American Cancer Society and NexCura represents a technological breakthrough that will help us assist individual cancer patients and survivors with accurate, personalized treatment information that is relevant to their individual situations," says **Harmon J. Eyre**, MD, the society's national chief medical officer.

"As the most trusted source of cancer information, with a 98% brand awareness, the American Cancer Society is in a unique position to support patients' treatment information needs. We are excited to provide applications to enhance its services," says **Eve M. Stern**, president of NexCura.

NexCura's Cancer Profilers link cancer patients with extensive databases of significant clinical studies. The Cancer Profilers generate unbiased, objective information tailored to patients' individual medical situations and concerns. Information available from Cancer Profilers includes:

- full disclosure of treatment options for their specific disease states;
- risk tolerances for treatment options;
- potential side effects of treatment options;
- questions patients can ask their physicians;
- possible treatment outcomes and survival statistics.

The information can be printed out to facilitate discussion with family members and support the patient-physician dialogue.

Each Cancer Profiler will be accessed on www.cancer.org through the site's Cancer Resource Centers for that form of the disease. To date, NexCura has developed Cancer Profilers for bladder, breast, cervical, colorectal, melanoma, ovarian, prostate, and uterine cancer. ▼

Pharmacy program links seniors with nebulizers

Walgreens Health Initiatives in Deerfield, IL, recently launched a pharmacy program that provides nebulizer medication, equipment, and health care services to Medicare beneficiaries with chronic respiratory conditions, including chronic obstructive pulmonary disease.

Many nebulizer medications used for respiratory therapy may be covered under Medicare Part B. Although some pharmacies do not offer billing services for covered Medicare services, Walgreens Health Initiatives accepts Medicare

assignment and reimbursement specialists will also bill supplemental or Medi-Gap insurance for qualified patients.

Walgreens Health Initiatives ships medication and equipment directly to the patient's home. In addition, patients receive refill reminders to help track reorder needs, and postage-paid reorder cards. Patients in the pharmacy programs receive phone calls every 30 days to ensure patients never run out of medication or supplies.

For more information on Walgreens Health Initiatives' nebulizer medication program, call toll-free (888) 906-6746. ▼

Check out workers' comp resources for case managers

LRP Publications in Horsham, PA, has two resources designed to help return claimants to work safely and keep case managers informed about new developments in workers' comp case law and other developments in the field. To order either of the resources described below, contact LRP Publications, Dept. 450, 747 Dresher Road, P O. Box 980, Horsham, PA 19044-0980. Telephone: (800) 341-7874. Fax: (215) 784-9639. E-mail: custserve@lrp.com.

• **2000 Workers' Compensation Year Book.**

This 508-page, soft-cover book summarizes the past year's significant developments in workers' compensation laws and judicial interpretations. It provides a comprehensive overview of issues you must know, including medical benefits, program costs, and disability benefits.

The book includes: tables comparing state workers' compensation laws as of Jan. 1, 1999; timesaving summaries of as well as the full text of more than 50 significant court decisions; updates on workers' compensation reform and selected state legislative developments; summaries of significant reports and surveys on workers' compensation issues, including medical costs, most common injuries, risk manager's opinions on global business and workplace violence.

Request product: #8000.DB00. Cost: \$57.25 plus shipping and handling.

• **Successful Return-to-Work Strategies.** This 28-page pamphlet details companies' successful return-to-work programs. It also explains the interplay between return-to-work policies,

workers' compensation, the Americans with Disabilities Act, and the Family and Medical Leave Act.

The resource includes: 10 components of a successful return-to-work program; low-tech ergonomic devices that reduce workers' injuries by as much as 80%; legal parameters of a light-duty program; communication techniques to ease the return-to-work process.

Request product: #8000.RTW.A. Cost: \$9.95 plus \$3.50 shipping and handling. ▼

Helpful tips are available for pacemaker patients

Pritchett & Hull Associates in Atlanta recently released the booklet, *You Have a Pacemaker: A Guide for People with heart failure*.

This informative 32-page booklet includes information on why a pacemaker is needed, how it is implanted, the different types of pacemakers and post-surgery instructions on acceptable activities. It is written in simple language with colorful illustrations designed to reassure patients that this is a safe and common procedure.

Topics covered include:

- care of the incision;
- clothes;
- medications;
- home appliances/microwave ovens.

The cost is \$3.80 plus shipping and handling, with quantity discounts available upon request. To order, contact Pritchett & Hull, 3440 Oakcliff Road NE, Suite 110, Atlanta, GA 30340-3079. Telephone: (800) 241-4925. Web site: www.p-h.com. ■

Send us *Resource Bank* items

If you have a new resource, conference, or seminar of interest to other case managers, send items for publication to: Lauren Hoffmann, Editor, *Case Management Advisor*, P.O. Box 740056, Atlanta, GA 30374. Telephone: (770) 955-9252. Information on conferences and seminars must be received at least 12 weeks before the event to meet publication deadlines. ■