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# Case Management

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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. 11.)

"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.

## **COMING IN FUTURE MONTHS**

- Setting caseloads: Results of exclusive national survey
- Accreditation — this time for vendors
- How culture impacts health behavior and medical outcomes
- Pharmacy consults improve outcomes, reduce costs in chronic care
- Legal issues in workers' compensation

"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.rsds.org](http://www.rsds.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.

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

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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*

**R**eflex 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.

### Special Report Managing RSD

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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.rds.org](http://www.rds.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

*(Continued on page 11)*

(Continued from page 6)

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 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.

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## 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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- Roughly 5% of respondents report being employed part-time due to RSD.
- Just over 21% report being employed but not 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:

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- 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 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.

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

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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](http://www.epii.com).) ■*



## 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