



99 Cherry Street
Milford, CT 06460
Tel: 203.877.3790
Toll Free: 877.662.7737
Fax: 203.882.8362
E-mail: info@rsds.org
Website: <http://www.rsds.org>

*Raising awareness of Complex Regional
Pain Syndrome (CRPS) and Reflex
Sympathetic Dystrophy (RSD) since 1984.*

Media Information

I Have CRPS

I have Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy Syndrome (RSD).

Physicians do not know why it develops or what causes it, but CRPS is a nerve disorder that usually occurs after a traumatic injury, surgery, sprain, fracture, or a period of immobilization. The principal symptom is pain dramatically disproportionate to the injury.

More than 140 years ago, Dr. Silas Weir Mitchell, a Union Army surgeon, first described the excruciating pain that we know as CRPS.

CRPS can lead to disability.

I may look "healthy," but I often suffer unbearable, unrelenting, and burning nerve pain. The pain associated with CRPS has been rated worse than that of people who suffer from cancer.

My skin may swell, sweat, change colors, change temperature, or hurt to the slightest touch.

CRPS can spread.

Often it is difficult for me to sleep so I may have trouble with attention and concentration.

I am frequently following a prescribed medication regimen that usually involves powerful drugs with many side effects that may affect my alertness or attentiveness.

It is often hard to move easily, or keep my body steady.

Chronic pain, like that caused by CRPS, often leads to depression because we undergo significant, and often negative, life changes.

I have good and bad days, even hours. Stress increases my pain.

Presently, there is no cure for CRPS, but there are several successful treatments. I always have hope because of the support of my family and friends.

Here's How You Can Help Me

Please believe that the pain is real even though it is invisible and may not be readily apparent in my demeanor or activities.

I am learning various coping mechanisms to get through the day, but the chronic pain is always there. I cannot predict how I will feel each day.

Sometimes it hurts to be touched anywhere, so please ask before you touch me.

It is OK to ask me about CRPS. Better yet, visit www.rsd.org and learn all you can.

What is CRPS?

Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy (RSD), is a chronic neurological syndrome characterized by:

- severe burning pain
- pathological changes in bone and skin
- excessive sweating
- tissue swelling
- extreme sensitivity to touch

Proposed Clinical Diagnostic Criteria for CRPS

Budapest Consensus Group

1. Continuing Pain, which is disproportionate to any inciting event
2. Must report at least one symptom in three of the four following categories:
 - *Sensory*: Reports of hyperesthesia and/or allodynia
 - *Vasomotor*: Report of temperature asymmetry and/or skin color changes and/or skin color asymmetry
 - *Sudomotor/Edema*: Reports of edema and/or sweating changes and/or sweating asymmetry
 - *Motor/Trophic*: Reports of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)
3. Must display at least one sign* at time of evaluation in two or more of the following categories:
 - *Sensory*: Evidence of hyperalgesia (to pinprick) and/or allodynia (to light touch and/or deep somatic pressure and/or joint movement)
 - *Vasomotor*: Evidence of temperature asymmetry and/or skin changes and/or asymmetry
 - *Sudomotor/Edema*: Evidence of edema and/or sweating changes and/or sweating asymmetry
 - *Motor/Tropic*: Evidence of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)
4. There is no other diagnosis that better explains the signs and symptoms

*A sign is counted only if it is observed at time of diagnosis.

Further information about the symptoms and signs of CRPS

RSDSA Clinical Guidelines: Diagnostic Considerations (PDF):

http://www.rds.org/3/clinical_guidelines/TXguidelines_Intro_diagnostic.pdf

Complex? Regional? Pain? Syndrome?: <http://www.rds.org/4/resources/images/veterans/SchottCRPSreview.pdf>

Schott GD. *Practical Neurology*. 2007;7:145-157.

National Institutes of Health: CRPS Fact Sheet:

http://www.ninds.nih.gov/disorders/reflex_sympathetic_dystrophy/detail_reflex_sympathetic_dystrophy.htm?css=print

History

CRPS was first described by Dr. Silas Weir Mitchell, a Union Army Surgeon, in 1864 after having witnessed the experience of injured soldiers in the Civil War. The suffering of one particular soldier with CRPS is described in some detail.

On the second day the pain began. It was burning and darting. . . . sensation was lost or lessened in the limb, and . . . paralysis of motion came on in the hand and forearm. The pain was so severe that a touch anywhere, or shaking of the bed, or a heavy step, caused it to increase.

Two years later the pain was still at the level where the soldier could not tolerate 'Friction of the clothes, at any point of the entire surface . . .' as this 'shoots into the hand' increasing his burning pain. He would allow no one to touch him 'except with a wetted hand, and even then is careful to exact careful manipulation.'

Injuries of nerves and their consequences: <http://www.rds.org/4/resources/images/veterans/SilasWeirMitchell.pdf>

Mitchell SW. Philadelphia: Lippincott; 1872;292-296.

About RSDSA

The Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) was founded in 1984 to promote public and professional awareness of Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy (RSD). A national not-for-profit organization headquartered in Milford, Connecticut, we also educate those afflicted with the syndrome, their families, friends, insurance and healthcare providers on the disabling pain it causes; encourage individuals with CRPS to offer each other emotional support within affiliate groups; and are committed to raising funds for research into the cause and cure of CRPS.

RSDSA is charged with increasing awareness of an underdiagnosed and undertreated syndrome. We welcome media inquiries about the syndrome, the people who are afflicted, and the physicians who treat them. Please contact us for:

- Expert analysis on a wide range of issues related to CRPS disorders
- Current data on research, treatments, rates of prevalence
- Interviews with national spokespersons and technical experts
- Access to persons with CRPS and their families who are willing to share personal stories with the media
- Comments on breaking news
- Arranging interviews with physicians and people with CRPS as requested

Organization At A Glance

Annual Report

http://www.rds.org/1/annual_report/index.html

Members

>6,000, (13%, receive free membership) <http://www.rds.org/1/membership/index.html>

Research

RSDSA is committed to encouraging research into the cause and cure of CRPS. Since 1992, RSDSA has funded \$1,300,749 in fellowships and grants. In 2008, we funded \$65,896 in grants. As of June 30, 2009, we have expended \$45,009 in grants in 2009. Recent RSDSA-funded Research (<http://www.rds.org/3/research/pdf/ResearchFlyer.pdf>)

Publications

<http://www.rds.org/1/publications/index.html>

RSDSA Review (Quarterly Newsletter) (http://www.rds.org/1/publications/review_archive/index.html)

In Pain, Out of Work, and Can't Pay the Bills, directory for financially-devastated members

(http://www.rds.org/4/resources/out_work/in_pain_intro.html)

Brochures and other educational materials (<http://www.rds.org/1/publications/index.html>)

Take Flight with Hope: Stories of Hope and Transformation (<http://www.rds.org/1/publications/pdf/BrochureHopeFINAL.pdf>)

Free information packets

Educational Initiatives

<http://www.rds.org/3/education/index.html>

Evidenced-based Clinical Practice Guidelines for the Diagnosis, Treatment, and Management of CRPS

(http://www.rds.org/3/clinical_guidelines/index.html)

Article archive of peer-reviewed medical articles on research, diagnosis and treatment of CRPS

(http://www.rds.org/2/library/article_archive/index.html)

Stories of Hope (<http://www.rds.org/4/stories/index.html>)

Website (<http://www.rds.org/>)

Electronic Alerts (http://www.rds.org/alert_subscribe.html)

Facebook (<http://www.facebook.com/pages/Reflex-Sympathetic-Dystrophy-Syndrome-Association-RSDSA/21827083946?>)

Twitter (<http://www.twitter.com/RSDSA>)

YouTube (<http://www.youtube.com/rdsaoamerica>)

Slide kit for professionals on diagnosis and treatment: http://www.rds.org/3/education/pdf/RSDSA_SlideKit_01062010.pdf

RSDSA exhibits at several major medical, health, and benefit insurer conferences