

**Background:** Complex regional pain syndrome (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. Unfortunately, we are finding more and more veterans returning from Iraq and Afghanistan who are suffering from CRPS or chronic pain.

This September, the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) was invited to exhibit at the VA/DOD Evolving Paradigms II, a national conference for personnel and organizations involving in caring for returning veterans of the Iraq and Afghanistan wars. While exhibiting at the Conference, it became apparent that some of the VA staff were not familiar with the treatment of CRPS or its telltale signs. After the DOD/VA Conference, RSDSA built a webpage with [Resources for Veterans with CRPS](#) linked from our homepage.

**Objective:** To reach out to veterans and military personnel with CRPS, as well as their caregivers, to determine how RSDSA can increase its support to veterans.

**Target Audience:** Veterans and Active Duty Military Personnel with CRPS

**Methods:** The Survey opened on December 15, 2009, and was sent to 7,204 subscribers. The Survey was composed of 24 questions (21 required), which placed the respondents demographically; asked about their experiences with CRPS, in the military, and with disability ratings; and queried RSDSA resources and membership status. The Survey closed on January 13, 2010.

**Results:** 19.9% (1,419) of the subscribers opened the survey invitation e-mail, and there were 78 survey responses (5.4%). 62.2% of respondents were either active duty military or veterans with CRPS, and were geographically distributed evenly. About 60% developed CRPS more than 5 years ago, and 67.9% of the total were not diagnosed promptly. Veteran-respondents saw an average of 5.7 healthcare professionals before diagnosis; and were diagnosed mostly at either a civilian medical center or by a private practice physician. Direct queries and personal accounts/stories are throughout, but more so in questions 5, 9, 11, 12, 19, 20, 22, and 24.

Detailed question-answer and text-answer results follow.

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1.\*

I am a/an:

Answer	0%	100%	Number of Response(s)	Response Ratio
Active Duty Member of the Military with CRPS			2	2.5 %
Veteran with CRPS			46	59.7 %
Family member, friend, or colleague of a Veteran with CRPS			9	11.6 %
Other			21	27.2 %
<b>Totals</b>			<b>77</b>	<b>100%</b>

**Other (21 Responses)**

Answer
contractor
I'll had RSD when for 6 years
I have RSD
person with CRPS
Private citizen
mother of child in military
I am not in the military.
Daughter of retired Navy officer
spouse of Veteran
crps patient
my husband is military
my sister was diagnosed with CRPS
non military and have RSD
police brutality
I have CRPA
mother with crps
work with veterans
nurse in home health
member of the public
civillan with CRPS
Veteren with wife that has CRPS

2. \*

Where do you live?

Answer	0%	100%	Number of Response(s)	Response Ratio
United States - Northeastern (Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont)			17	21.7 %
United States - Midwestern (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin)			10	12.8 %
United States - Western (Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, Wyoming)			18	23.0 %
United States - Southern (Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, Washington DC, West Virginia)			30	38.4 %
Other			3	3.8 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

Other (3 Responses)

Answer
Florida
Guam
Great Britian

3. \*

Which war are you a veteran of?

Answer	0%	100%	Number of Response(s)	Response Ratio
Vietnam			14	17.9 %
Gulf War			8	10.2 %
Iraq			2	2.5 %
Afghanistan			1	1.2 %
Not applicable			38	48.7 %
Other			15	19.2 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

### Other (15 Responses)

Answer
Colombia and Peru
Iran hostages communications 1980-81
Not a veteran
gulf war era
husband was in Vietnam
Retired: Served 1979-2002
Gulf war era
Cold War
peace time service
no
post-Vietnam
Navy, but not war vet
Lebanon Conflict
Vietnam era
iraq and bosnia

### 4. \* How long ago did the CRPS develop?

Answer	0%	100%	Number of Response(s)	Response Ratio
Less than 6 months			1	1.2 %
6 months to 1 year			1	1.2 %
1 year to 3 years			17	21.7 %
3 years to 5 years			12	15.3 %
More than 5 years			47	60.2 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

### 5. \* How did you develop CRPS?

#### 75 Total Responses

#### Active Duty Member of the Military with CRPS (2 Responses)

Answer
After osteotomy surgery on left knee in Oct '06
Through an injury at work in 2005

#### Veteran with CRPS (45 Responses)

Answer
industrial accident-left wrist crushed in hydrolic welder
don't know

Surgery
Rape from supervisor escort. fear of life from guards and the control the supervisor had on my ability to survive area. The treatment from VA and others attitudes that we were prostitutes for the males. told no PT, Counseling no, put arm in brace from pinched nerve rt. handed over a year before I got pregnant to get out which gave significant relief of symptoms. Noted in many women medical issues groups pg reduce symptoms. Over 20 years until I was able to establish the mental disability. VA still deny RSD service connected. don't qualify for most treatments not War time service. Congress did not approve our mission under Pres. Carter after election no authority and neither Did Pres. Reagan. so PTSD issues every election year of change Pres. Don't qualify for PTSD. by a couple of points. Lack of continuity of military care due to overworked staff and my care does not get much if any funding/pennies on the dollar compared to what ever congress funds. Look at the Bill. PTSD bye
post trauma
several traumatic injuries to my right foot and ankle, culminating in a fusion of the right ankle after the joint, cartilage, synovial membrane were destroyed, received stab and bullet wounds in right leg. (at different times) and has progressed with several back injuries, fractures, falls mostly from right ankle instability before the fusion. Then had my right kidney removed in January 2008 for a renal mass.
began with fractures in my left foot which did not heal properly.
Fell from a Horse, Crushed Pelvis
accident dislocation of left ankle
Injury to the heel of the left foot sustained during basic training at Ft. Jackson,SC (2003)
From an accident where i fell off some steps. I dislocated my knee, broke my leg in 4 parts and broke my ankle. My ankle was never treated and that where it started.
Don't know for sure. By the end of training I had to buy two different sizes of boots. Feet always hurt
Following surgery on my elbow for Ulnar Tunnel Syndrome, and a medial epicondelectomy. I had the surgery on both elbows over a four month period in 1993.
I developed CRPS back in 1992 after getting a hair line fracture of my right scapula. I received nerve blocks and pain meds for 2 years before undergoing a sympathectomy. After the surgery there was no improvement. I have been on pain meds and meds for nerves to try and control the pain level. The pain radiates down my right arm and into my hand, which makes it difficult at times to work since I am right handed and a Programmer/Analyst. I do find that in cold weather the pain increases. The pain also increases when I spend a lot of time at the computer, which unfortunately is my job.
I was exposed to Sarin Gas (long term, low dose) and also to Oil refinery fires. One day had slight pain, like a twisted ankle. Within a week I was on crutches, and couldn't use my foot or leg.
I was injured during combat training, and the follow-up corrective surgery caused the onset of RSD. I jumped into a foxhole and fractured my tailbone against a rock that I didn't see. I also herniated my L5-S1 and L4-L5. I had a double laser discectomy to repair the herniated tissue. Two days after this surgery, I had the burning sensation appear on my right lower leg. The neurosurgeon explained that the laser barely nicked my sciatic nerve and this probably caused the RSD sensations. He recommended a followup surgery, a full laminectomy of my L5-S1. This was done and of course, the burning sensations spread to both legs and my feet. The nerve roots were fully cleared and nothing was physically irritating the nerves (full workup at Walter Reed Army Hospital). After 3 long years, I finally received a diagnosis of RSDS and was allowed to retire after 22 years service. I have a 100% disability rating and am fully disabled for SSA purposes.
A routine ankle injury/sprain progressed to burning pain which would not subside. It was misdiagnosed as various problems such as tendonitis for over a year during which time the treatments I was being given were actually contraindicated for RSD/CRPS. The prolonged wait for a correct diagnosis plus inappropriate treatments which actually exacerbated the RSD/CRPS led to it becoming permanent and spreading from the right left lower extremity only to the entire right side of my body.
After having Carpel tunnel release in 2/93, I developed severe pain and swelling and the pain has never left.
I had my tibia/fibula and ankle broken during a combat related martial arts practice at Marine Corps Boot Camp.
3 surgeries due to Frieberg's disease, avascular necrosis of the L 3rd metatarsal subsequently developed severe pain initially L foot then gradually up lateral side of lower leg, chalked up to my original diagnosis and post operative changes for a long time before diagnosed with CRPS
I was injured playing football for the Marine Corps.I also while on leave had a bad car accident and was on light duty for months.I also had psychological problems. After the service I lost my left leg in a motorcycle accident.I had over 40 surgeries and died twice and was revived...I was shot once and wwhen I put a claim in to raise my benefits I'm alway's turned down.I have been 10% since 1979. I have severe chronic pain and deprssion. I get treated by Pain clinics and my doctor treats my pain with methadone 10mg 3 tabs 4 times a day and soma for muscle cramps. I'm married 7 years and my wife is very psycotic.She just walked in and said we need a divorce. I can't take any more emotional abuse. She accuses me of everything. It increases the pain I suffer from 24 hours a

day. I need help we live lower than 400% lower than the poverty level I can't live like this anymore.
I had surgery on my right wrist arthritis and work had removed the cartilage in the joints of my right hand. I had surgery it got infected two surgeries latter they told me I had crps.
I was injured in the Marine Corps while on a training exercise. It torn some of the soft tissue in my right lower extremity and required surgery to repair the damage. After the surgery, I was in more pain and more disabled than ever in my life. It was not long after that that I got a Staph infection in the same limb at the site of some of the stitches. Pain was my ever present companion and I had a new label, RSDS. The subsequent pain and diagnosis ended my Marine Corps career.
Had my right hand crushed in an industrial accident in 1994. I had 1500 hundred pounds of steel lowered on my hand. It then spread to my shoulders, back and both legs and feet.
I was playing basketball and came down with the rebound and did a perfect split in 1986. I fell in 1999 and tore my ACL. I had ACL replacement surgery in February 2000. Since that surgery I continually had swelling and pain in my left knee. The doctor went in my knee two more times with the scope. In June 2004, the doctor at Hampton VA Medical Center diagnosed me with RSD. My pain still continues to get worse and in December 2008 I was diagnosed with fibromyalgia.
Knee replacement surgery. December. 2007
I was in basic training and was doing the 2 mile run for PT, my ankle went in and I heard a pop and snap, I went down, drill instructor did not believe me that I hurt myself and had me do a grass drill, I went to sick call, all they could see in the x ray that my ankle was swollen, the swelling never went down and the pain never went away it only increased
Broke bone in foot
I sprained my ankle.
Morton's Neuroma developed at AIT, had surgery at MAMC to remove and CRPS was the result. As to question 6, the civilian sector diagnosed me within a few months and a few doctors and the military docs, although they did their own investigations and used the correct method to diagnose, took many months to receive appointments and proper care for CRPS
I was doing a job related to the Bomb Dump, warehousing job that I was trained to do. All of a sudden a pallet strap wrapped around my ankle and I fell face first, just missing a stack of pallets.
On April 5, 1968 as member of Illinois Army National Guard, was activated by Presidential Executive Order 11403, providing assistance for restoration of law and order in the state of Illinois. I was stationed at McKinley Park, Chicago, Illinois. On first day I was on patrol for 18 straight hours. When I removed my boots after patrol both of my feet were swelled about 1 inch out on bottom. I was refused medical attention even though I made the request several times. This trauma to my feet is the cause of my RSDS/CRPS, which laid dormant from 04/05/1968 to 10/20/2003 when I told a Doctor at the VA Medical center in Louisville, Kentucky that I had RSD and had burning (9-10) pain in both legs. This Doctor prescribed Neurontin which took 21 months to get only with the help of Jim Broatch at RSDSA who put me in touch with the National Pain Consultant for The VA, Mr. Robert Kerns. Within one week of making contact with a Mr. Robert Kerns I had the Neurontin, pain dropped to a 2-3.
Developed shin splints and stress fractures in boot camp in the US Navy and then that developed into CRPS.
It was diagnosed by three physicians within two to three weeks following bilateral foot surgery to correct Morton's Neuroma's. The CRPS developed at the same time in both feet.
I was in a motor vehicle accident
Working on C141 cargo plane. The emergency escape hatch handle caught and twisted my arm causing RSD / CRPS in my right arm. I currently use a spinal cord stimulator to help control the pain.
No known apparent cause-I was awoken during the middle of the night when suddenly the pain appeared in my upper left arm. I had a desk job, not particularly active and nothing out of the ordinary happened in the months preceding it.
I was a military working dog handler in the USAF. I received between 5-10 dog bites to include a dislocation in my right hand and arm. I was also a Raven in the AF. While training in Afghanistan for my Raven duties my right wrist popped. I was x-rayed for a break, but there wasn't a break; I was returned to my duty station and went through therapy and other treatments that did not work. Finally 3 months after the injury I was shipped to Hickam and treated at Tripler Army Hospital where they did a bone scan and determined I have CRPS and was then treated by a civilian specialist until I was retired and returned to Missouri.
From injuries I receive from a fall while I was building a church on Merritt Island, FL. (VISN 8). Due to my totally debilitating injuries, my wife and I have returned to Ohio where we both were born and have family. The VA awarded me 100% permanent disability but is clueless about CRPS in VISN 10 (Ohio). They think I am drug seeking - this is not the case, I want my pain managed with what I know works. They have given my wife and I nothing but grief since returning to OHIO. VISN 10's maltreatment of me is causing significant mental anguish with outbursts of rage. So much is this, on some days I will not even engage people outside of our home.

<p>1. CRPS (Complex Regional Pain Syndrome) type II, dx August, 2009 @ University Hospital, Case Western in Cleveland.</p> <p>a) Right knee  b) Left forearm anterior near and lower to the elbow.  c) Left &amp; Right shoulders; predominantly the left.</p> <p>2. L4/L5-S1 Herniation dx 1993 and degenerative disc "DDD dx 1995.</p>
<p>I was crushed between two car bumpers on August 31, 1997, resulting in multiple severe crush trauma to lumbar, pelvis, abdomen, and left leg. Left knee was ripped apart as well as the tibia and fibia shattered resulting in massive nerve damage and leaving the left foot essentially paralyzed with no movement or sensation from above the ankle down. In Jan 1999 my left foot swelled to enormous proportions and began hurting; I was then diagnosed with RSD and placed on Neurontin.</p>
<p>A nerve was cut during a military surgery. It was a mistake.</p>
<p>fell down 2 flights of stairs</p>
<p>FROM AN OPERATION ON MY RIGHT ARM/ELBOW</p>
<p>Leg damage from a fall.</p>
<p>after leaving the army i was working as an engineer / brakeman for a short line railroad and had a lid of a railcar crush my leg</p>

Family member, friend, or colleague of a Veteran with CRPS (9 Responses)

<p><b>Answer</b></p>
<p>I was a VA Nurse working on the Geriatric Unit at our local VA Hospital. While doing daily care for one of our patients that had a history of abusing the staff, he grabbed my thumb and pulled it up behind me touching the back of my head. I tried to get out of the hold but it only made it worse. Finally one of the other Nurses came in and she had to pry my thumb away. By this time the damage had been done. He had torn every tendon, ligament in my thumb. I can't even explain. The VA doctor casted it wrong by putting it in a Spica position which caused severe Nerve damage. When I started to have severe burning pain along with pain I had for months they sent me to a Pain Management Specialist. After many tests, my diagnosis is now CRPS/RSDS which has begun to spread to other parts of my body. I am in stage 4 and not a whole lot more they can do for me. I live each day with this pain because of an angry old man.</p>
<p>Several months after having shingles on the torso hurt back while doing yard work. Next morning experienced excruciating pain on right side of body from shoulder, down arm to fingers and RH side of torso. Constant pins &amp; needles pain with frequent lightning bolts down arm to middle finger.</p>
<p>It just started one day and has never stopped. the Dr dont know what happen.</p>
<p>broken right leg femoral bone.</p>
<p>On July 5 2000 an injury do to a turbo charger in an engine sucked my husband's hand into the blades. His hand has been in pain ever since and gets worse each year. He was not diagnosed until 2008 when seeing a pain specialist not with the VA but does treat them when re-fared.</p>
<p>Falling through a crane in work</p>
<p>My husband developed CRPS after the Navy started to do surgery on him and put a nerve block under his arm pit. That was more than 20yrs ago and I didn't know him then. We have only been married 9yrs so I don't exactly. He had a stroke two years ago and can't speak so all is lost. When he had the stroke get had CRPS all over his body and was in a lot of pain. Now it is hard sometimes to know if the systems he is having is from the stroke or the CRPS.</p>
<p>After surgery, for the person in my family.  As noted, I work with veterans for return to work and retraining, in voc rehab.</p>
<p>Dislocated and broke ankle. Was not reduced for 4 hours. Then had to wait 10 days for surgery since they waited so long it was to swollen.</p>

Other (20 Responses)

<p><b>Answer</b></p>
<p>After a minor car accident. Pain, swelling and discoloration is inappropriate to injury.</p>
<p>I was a Truck Driver for 20 years and twisted my left ankle, and when I got in the truck and pull in the clutch. Pain went all the way my left side.</p>
<p>I was struck in the neck/shoulder region with a 60 pound auto part.  I fell,broke my collar bone,tore my rotator cuff and dislocated my ball and socket joint .All this is on the left shoulder.</p>
<p>ACL revision surgery with no nerve block</p>

then spread by IV venipuncture and trauma to other hand restarted by flu shot then worsened by botched stellate ganglion block into brachial plexus
Broken left wrist
I had A.L.I.F SURGERY (LUMBAR FUSION; L4 L5)
Auto accident 20 years ago caused by a drunk driver.
After injury to left shin by being impaled with a foreign object with force. Subsequent to an infection and femoral nerve injury.
Twisted running at work
fractured wrist
I had a knee surgery it became infected.
My sister fell off a ladder and broke her arm.
By Police Brutality
I had a bi-lateral release on both knees in march 2006. I was diagnosed in December 2006 after my physcial therapy started going south and the pain heightened
car accident
After surgery, for the person in my family.
As noted, I work with veterans for return to work and retraining, in voc rehab.
Severe injury to my right wrist after a fall crushed both bones in the wrist and the scaffold as well, they had to be pinned and and external fixation was applied for 6 weeks before having them removed. Displayed symptoms from the beginning but was not diagnosed with CRPS for several months then treatment was started.
After operation on my hand
knee surgery
My wife developed CRPS following ankle surgery, during with a nerve in her foot was cut. After the surgery, she kept telling me that her foot was wrapped in a band of ice... and I could see discoloration.

6. \* Were you diagnosed promptly?

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			25	32.0 %
No			53	67.9 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

**Veteran with CRPS (46 Responses)**

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			14	30.4 %
No			32	69.5 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

**7. \*** How many healthcare professionals did you see prior to a diagnosis of CRPS?

1 = 1, 2 = 2, 3 = 3, 4 = 4, 5 = 5, 6 = 6, 7 = 7, 8 = 8, 9 = 9, 10 = 10+

	1	2	3	4	5	6	7	8	9	10	Number of Response(s)	Rating Score*
											78	5.2

\*The Rating Score is the weighted average calculated by dividing the sum of all weighted ratings by the number of total responses.

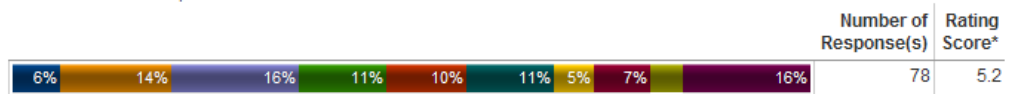
**Details**

1 = 1, 2 = 2, 3 = 3, 4 = 4, 5 = 5, 6 = 6, 7 = 7, 8 = 8, 9 = 9, 10 = 10+

1	2	3	4	5	6	7	8	9	10
5 (6%)	11 (14%)	13 (16%)	9 (11%)	8 (10%)	9 (11%)	4 (5%)	6 (7%)	0 (0%)	13 (16%)



Hold the mouse over each color of the bar to see the number of respondents.



**Veteran with CRPS (46 Responses)**

1 = 1, 2 = 2, 3 = 3, 4 = 4, 5 = 5, 6 = 6, 7 = 7, 8 = 8, 9 = 9, 10 = 10+

	1	2	3	4	5	6	7	8	9	10	Number of Response(s)	Rating Score*
											46	5.7

\*The Rating Score is the weighted average calculated by dividing the sum of all weighted ratings by the number of total responses.

**8. \*** Where were you diagnosed?

Answer	0%	100%	Number of Response(s)	Response Ratio
Military Medical Center			9	11.5 %
VA Medical Center or Clinic			6	7.6 %
Civilian Medical Center			19	24.3 %
Tertiary Care Center			0	0.0 %
Private Practice Physician			37	47.4 %
Other			7	8.9 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

### Other (7 Responses)

Answer
Hospital RSD specialist
NEUROLOGIST IN Bethesda, md
Ohio State University
First by Civ doc then By MMC
Functional Imaging and Assessment of Kentucky
At a military center, but as a dependent
neurologist took test

### Veteran with CRPS (46 Responses)

Answer	0%	100%	Number of Response(s)	Response Ratio
Military Medical Center			7	15.2 %
VA Medical Center or Clinic			5	10.8 %
Civilian Medical Center			13	28.2 %
Tertiary Care Center			0	0.0 %
Private Practice Physician			17	36.9 %
Other			4	8.6 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

### 9. \*

Do you also have other conditions that resulted from the initiating event?

Answer	0%	100%	Number of Response(s)	Response Ratio
Posttraumatic Stress Disorder (PTSD)			16	21.3 %
Traumatic Brain Injury (TBI)			0	0.0 %
Amputation(s)			2	2.6 %
Not applicable			37	49.3 %
Other			25	33.3 %
<b>Totals</b>			<b>75</b>	<b>100%</b>

### Other (25 Responses)

Answer
Anxiety
muscle atrophy,loss of use of arm,
postural orthostatic tachycardia syndrome
TMJ
Stellate ganglion block
Spinal stenosis
LBP
Short term memory loss.
back pain

Spinal Cord Stimulator
Fibromyalgia
brain tumor
Severe Back Pain
numerous surgery
Please see below
anxiety
loss of use of the limb and atrophy
Surgery
fibromyalgia
knee replacement
depression and anxiety
Situational Depression
seizures
no
Medication Side Effects

### Comments (21 Responses)

Answer
Due to the medications I have to take every day, it has caused my vision to get worse, also it has damaged my teeth. This is documented on each of the medications side effects.
past year did get TMJ service connect due to mental . Me gritting teeth for five years of pain and further insult to injury. I had surgery with teflon in fossa 85. minisectomy. removed 92 with lg cell granuloma and now necrosis condyles. digestive problems constipation etc etc side effects of meds not monitored appropriately
Received stelate ganglion blocks that were unsuccessful. Last block, injured a nerve in my neck and I still have a large hemotoma in the area after 18 months. Now have developed shoulder pain and upper arm pain
During the diagnosis phase it was found that he had spinal stenosis of the cervical spine. The pain presented in March 2003. 9 months later he underwent surgery to replace the disc between the 5th & 6th vertebra, which improved the pain only slightly.
It is incredibly uncomfortable, wakes me up, I feel like taking a bat to my leg and maybe it would feel better.
I seem to short term memory loss as a result of the car accident. Is it a cause & effect from the RSD or is it from the medication?
Yes, I have lower back pain from the change in gait due to the injury.
Have rheumatoid arthritis in both feet.
With only about 30% pain relief.
it started many other problems. I now have neuropothy, I have had over 20 surgery's, I have reflux and now my stomach is giving me problems do to the meds I take. OH WELL, COULD BE WORSE
Failed back surgeries, skeletal arthritis, spinal stenosis, etc.
vertigo, rsd, chronic pain syndrome, degenerative disks
My ankle bone didn't set properly and now I have severe limited range of motion aside from the limited range as a result of the RSD/CRPS
Just the nerve block and for some reason the didn't remove the cyst on his hand after they had done this.
Had index finger and quarter of my right hand amputated.
The military acknowledged my RSD as service connected but denied the fibromyalgia as service connected. Their reasoning was that fibromyalgia is caused by mental health issues.
The PTSD is from being in the Gulf War, plus rotator cuff tendinitis.
I went from not taking perscription drugs , To worrying if I have taken my pills on time.
I had a severe whiplash which was the initial injury.

The conditions I suffer from are based from my medications which include dizziness, loss of memory, lack of concentration, decline in verbalization. I also suffer hyper stimulation in my right arm from shoulder to fingertips; when touched with anything as light as a feather, it feels like a thousand needles.

Unsure of PTSD, no Dx, but show signs of the symptoms; undiagnosed at this juncture.

### Veteran with CRPS (46 Responses)

Answer	0%	100%	Number of Response(s)	Response Ratio
Posttraumatic Stress Disorder (PTSD)			13	28.2 %
Traumatic Brain Injury (TBI)			0	0.0 %
Amputation(s)			2	4.3 %
Not applicable			21	45.6 %
Other			12	26.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

### 10.\*


Where do you currently receive your medical treatment?

Answer	0%	100%	Number of Response(s)	Response Ratio
Military Medical Center			2	2.5 %
VA Medical Center or Clinic			20	25.6 %
Civilian Medical Center			12	15.3 %
Tertiary Care Center			1	1.2 %
Private Practice Physician			30	38.4 %
Other			13	16.6 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

### Other (13 Responses)






Answer
my condition is not fixable
VA and holistic center
pain mgmt. dr.
Workmans Comp doctor
VA and private practice physicians
none
va and civilian
Im in remission
n/a
Matrix Pain Mgmt in Saginaw, MI
private MD, & VA for medication
not have treatment at the moment
VA Medical Center - VISN 10 and Private when I can afford

**Veteran with CRPS (46 Responses)**

Answer	0%	100%	Number of Response(s)	Response Ratio
Military Medical Center			0	0.0 %
VA Medical Center or Clinic			18	39.1 %
Civilian Medical Center			9	19.5 %
Tertiary Care Center			0	0.0 %
Private Practice Physician			12	26.0 %
Other			7	15.2 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

**11.\***

Which treatments have you used to manage your CRPS?

Answer	0%	100%	Number of Response(s)	Response Ratio
Behavioral Approaches (such as biofeedback, cognitive behavioral therapy [CBT], mindfulness-based stress reduction [MBSR], exposure therapy)			29	37.6 %
Functional Restoration Approaches (such as graded motor imagery, mirror therapy, physical or occupational therapy)			39	50.6 %
Interventions (such as blocks, spinal cord stimulation, intravenous ketamine or lidocaine)			58	75.3 %
Medications (such as anticonvulsants, antidepressants, opioids [narcotics], SNRIs, NSAIDs, topical applications)			71	92.2 %
Other			11	14.2 %
<b>Totals</b>			<b>77</b>	<b>100%</b>

**Other (11 Responses)**

Answer
no medication
kineasiology
survival training
accupuncture
intrathecal pump
lyrica; 450 mg daily
hot tub
implanted spinal stimulator and intrathecal morphine pump
3x a wk Chiropractic care
therapy
spinal cord stimulator

## Comments (26 Responses)

Answer
breathe massage etc etc prayer meditation epson salt baking soda baths
Currently only relying on medications.
I am on a steady infusion of Fentanyl now with oral meds for breakthrough pain
14 blocks, spinal cord stimulation, occupational therapy, physical
Blocks only work for a short time. Intravenous ketamine seems to be a little better.
I currently use all of the above to manage my CRPS.
I had a tens unit, it made it feel very good while i used it, but when i stopped, it was worse that before i used it. I can't wear shoes, i can't stand anything touch my leg and foot. My foot, leg and knee burn like they have acid on them almost all the time. I condition has never gotten any better, but it has gotten worse. I wouldn't wish this on my worst enemy. I pain is so unbearable, but i work because i can't live on the little bit of SS i could get.
n/a
Physical therapy and blocks did not work. Have had spinal cord stimulator for one year.
Nothing really relieves the pain. I have learned to live with most of it, at times there is not relief. I believe it has gone from my foot to my knee.
Have tried all these at some time in the past. I have a spinal cord stimulator, but it is inoperable due to lead wires breaking. Since I am able to walk right now (with a walker or cane,) docs do not want to replace it.
my husband is allergic to all antidepressants, and morphine and Benzedrine
I only take 4 meds and the rest I feel the Lord will do what he says he will do and I have had no problem wiht things. I'm not saying it has been easy but I put my faith in the lord any day of the week rather than being drugged up all the time.
I initially was given the spinal stimulator; unfortunately, for the stimulation effect to reach my feet and toes, the amplification had to be at maximum. This was extremely painful in, umm, other areas. Therefore, I was given my first morphine pump five years ago and a few weeks ago had my second pump implanted. The two combined have improved my quality of life dramatically; however, I am never, ever pain free.
the blocks do not work. It made my condition worse. I was put on many meds and quit them all. I only utilize chiropractic care 3x/wk and utilize percocet(pain), and meclizone(vertigo). What has helped me deal with my condition on a daily basis is the chiroprtic care. W/O it I would be like a vegetable. Pain pills help eaze the pain.
My husband found that taking Lortab and a muscle relaxer plus guided imagery helped the most before the stroke.He did go to the VA in Mountain Home Johnson City TN till he had the stroke and they said it would be easier for him if he got a doctor on the outside closer to home.
I have a Spinal Cord Stimulator for 7 years.
None of these have helped with my pain.
Have tried them all , by the time it was diagnosed it was to late for some of the treatments and when I was diagnosed by a civilian doctor the VA did not acknowledge it
Spinal Cord Stimulator
After 8 years with CRPS my treatments have run the gamut, although I believe the most innovative and beneficial treatments happened while I was using Civilian health care. I can't argue that I would be completely destitute without the VA's care, and that they are doing as much as they possibly can with what they've got and they've always tried to accommodate my requests. When I got into the VA was the first time I was able to receive mental health treatment which has been incredibly helpful.
I guess I am lucky as my Primary Care Doctor (DR. Gregory G. Skaggs) at the VA Clinic in Clarkson, Kentucky, has RSD himself, so he knows how to treat RSD. Dr. Skaggs is the first doctor in the VA to extensively document my RSD. The VA has never diagnosed my RSD from October 20, 2003 until Dr. Skaggs in 2009.
I have also had a neuro simulator implanted to help with the pain.
I do NOT buy Behavioral Approaches, this is a Physical injury issue and only time will heal it; and PHYSICAL Interventions DO NOT work. I have found what works (MEDs); VISN 10 refuses to even acknowledge the correctness of my choices. Here are the modalities all were mostly ineffectual or momentarily effectual: Lumbar sympathetic nerve block 09', All Physical Therapies (L5/S1) 94'-09': Hot tub & warm water jet therapy, Hot Water, Tens, Traction, Ineffectual, severe pain. Ultrasound 93-94.
Nerontin from onset in '99 through 2003 when effectiveness was gone. Tried Lyrica in Jan '08 and it worked great, but Medicare would not approve it, more neurontin with no effect. Began epidurals and lumbar sympathetic blocks in 2008 leading to RF nerve ablation in 2009 until tired of so much agony for so little relief. Currently self medicating

with medicinal cannabis, which works very well.

i have a spinal stim implant connected to my spinal cord. i am also on a ton of meds

### Veteran with CRPS (46 Responses)

Answer	0%	100%	Number of Response(s)	Response Ratio
Behavioral Approaches (such as biofeedback, cognitive behavioral therapy [CBT], mindfulness-based stress reduction [MBSR], exposure therapy)			20	43.4 %
Functional Restoration Approaches (such as graded motor imagery, mirror therapy, physical or occupational therapy)			26	56.5 %
Interventions (such as blocks, spinal cord stimulation, intravenous ketamine or lidocaine)			38	82.6 %
Medications (such as anticonvulsants, antidepressants, opioids [narcotics], SNRIs, NSAIDs, topical applications)			43	93.4 %
Other			7	15.2 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

### 12.\*

Do you feel as though you are receiving the appropriate treatment(s) to manage your CRPS?



Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			43	55.1 %
No			35	44.8 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

### Comments (33 Responses)

Answer
I honestly don't think there is nothing else they can do as most physicians do not believe in this diagnosis.. Too bad they couldn't spend just one day in our shoes. One day of this pain from Hell with change their minds in a hurry..
There is no treatment that is acceptable. Too many deadly risks.
not through the VA or SSDI. out of pocket for things that do no harm
First let me say I think they are doing the best they can considering the education they have but I don't feel the doctors I see are aware of this condition to the extent they can offer the best possible treatment. I meet many veterans who also have chronic pain issues and like me, have seen many doctors seeking help.
Seems very hard to get total understanding of the quality and difference in pain and that sometimes it can relieve, but can return quickly and with a great intensity. It seems the doctors think if they dont see it while your there, its not of great importance.
I was under the impression that eventually it would go away. It's been almost 3 years and no change!!
It is questionable at times. I have a hard time answering this question. As long as my stress level is low the RSD seems to be under control. I am not able to keep the stress down because of financial hardship. Husband loss job over a year ago so I am working instead of taking care of myself.
Currently yes. Unfortunately, the Army was unable to diagnose me. It took 4 years and 13 M.D.'s to get me to a

specialist that was able to diagnose the problem.
Yes and no. I know a little about this but not enough. My pain meds control some of it, but i am always in very bad pain. I also use lidacaine pads and creams for the burning.
n/a
Masking the symptoms does not find the cure for the pain. The spinal cord stimulator and medications don't even make it possible to live a productive life. I am very limited to my activity due to pain.
I believe as much as can be done at this point has been done.
Everyday my husband has to fight to get out of bed because of the pain. He doesn't sleep until total exhaustion over takes him and then if he gets 2 hours that is considered a lot for him. The pain is horrific and many of the doctors still think he is faking.
I am doing what feels best for me. Everyone is different. I do not belive in the surgery. I am worse now since the blocks and the surgery. I am damaged for life and still trying to find a lawyer to fight my case
The RSD/CRPS has never trully addressed. I'll see a "specialist" and after their test rules out their field of eperitise I and dropped from the caseload.
Took several years to be diagnosed.
I can't find a doctor that knows much about it.
They just kind of forgot about his CRPS since the stroke.
Now after years of personal research and pushing to get the care.
The SCS has really helped,I was walking with 2 canes and also using a wheelchair.Since the SCS no more canes or wheelchair.
Physical and Occupational Therapy put me into remission and I have been in that for almost 1 year after trying every other typical and non-typical treatment
All the doctors want to do is keep changing the medication. From vicodin, percocept, morphine, morphine, gabapatin and not to mention the antidepressants.
Appropriate, yes. Effective, no
Throughout my time with the VA in NH it has been a struggle , I have been shuffled around all over the place , all I ever got from them was we have no idea what it is but it is getting worse
I am managing my CRPS, although I am not at the point physically or mentally that I would like to be at. I'm hopeful that there will be new treatment options coming over the next few years that will help me get into a healthier lifestyle so that I can look forward to each day.
AM on 800Mg Gabapentin 3x per day; 200Mg Trazadone at Bedtime for sleep and 100Mg Tramadol 4x per day.
This difficult to answer to because of the word appropriate. I have a SCS and take numerous medication but continue to have moderate to severe pain.
pain is difficult to manage and VA does not provide all medications.
But it has taken over a year and still the pain is not managed well.
I have significant experience in managing my pain from the injury in 94' and have FULLY researched ALL alternatives. Regardless, Pain Management in VISN 10 is more that just a little arrogant. I have a totally contrasting Pain Management experience in VISN 8. This is NOT an isolated incident - someone PLEASE HELP US IN VISN 10. PLEASE!!!!!!
My wife's current military doctor just told us yesterday that he does not believe she has CRPS - after 6 years! He now says that she has fibromyalgia - which she might - in addition to the CRPS. WHY do doctors keep doing this to her?
The VA isn't really good with CRPS
As far as I know.

### Veteran with CRPS (46 Responses)

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			26	56.5 %
No			20	43.4 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

13. \*

What is your current pain level? (0=no pain; 10=worst pain imaginable)

1 = 0, 2 = 1, 3 = 2, 4 = 3, 5 = 4, 6 = 5, 7 = 6, 8 = 7, 9 = 8, 10 = 9, 11 = 10

	1	2	3	4	5	6	7	8	9	10	11	Number of Response(s)	Rating Score*
												77	7.2

\*The Rating Score is the weighted average calculated by dividing the sum of all weighted ratings by the number of total responses.

Details

1 = 0, 2 = 1, 3 = 2, 4 = 3, 5 = 4, 6 = 5, 7 = 6, 8 = 7, 9 = 8, 10 = 9, 11 = 10

	1	2	3	4	5	6	7	8	9	10	11
	0 (0%)	2 (2%)	3 (3%)	8 (10%)	8 (10%)	7 (9%)	10 (12%)	16 (20%)	10 (12%)	7 (9%)	6 (7%)



	1	2	3	4	5	6	7	8	9	10	11	Number of Response(s)	Rating Score*
	2%	3%	10%	10%	9%	12%	20%	12%	9%	7%		77	7.2

Comments (27 Responses)

Answer
just had a massage afternoon need to soak
The meds keep it to between a 6 and 8.
On any given day, and depending on how much morphine I take, my level of pain will vary from a 6 to a 9. Once or twice a week it gets worse than that and I have gone to the ER with a 10 twice in the last four months
Can fluctuate-always a 2
only if I take my percocet and lycira is it tolerable...
When I dont do a lot my pain is a 3 or 4 an if I do a lot it is 10 to 20 an im in bed and can't move my arm my rsd is in my right arm and hand.
I am waiting to go into hospital for intravenous ketamine treatment.
My pain ranges from around 5 to as high as 10 on occasion.
Gets worse when I am working. As of December, I have been unemployed since April. In part because of the pain control meds I was taking.
It varies during the course of my day. From 8 in the AM to 4-5 later in the day. All related to medication blood level.
It varies from moment to moment, but it always present.
in the beginng it was over a ten now it is always a 3 don't know what else to say.
my vertigo is worse than my pain lately
The pain ranges from a min of 2 to 10 on a daily if not hourly basis.
varies each day
He is taking alot more meds now for pain.
I now have a Medtronic SCS.
The SCS really helps.
Had an exam today in reference to my claim. X-ray tech even though I informed him that the postioning of my knee and leg would cause pain, still had me take the x-rays. I was actually crying tears of pain. Pain is still hurting. This was at 8:30-9:00 am this morning.
I have suffered with CRPS for 10yrs , I now have loss of muscle dexterity , the pain is more intense , memory loss is more prominent, it has taken over my whole right side of my body , my whole right side feels like it is on fire most days
For the people I work with, 3-8/10

Varies depending on the weather and if I'm on my foot too long plus stress level.

I've had a lot of extra stress lately which has made my CRPS worse than normal, although it's still early today which is why I'm at a 6.

My pain level sometimes has me climbing the wall.

2-4 is my base-line

With the neuro stimulator on my pain is about a 6 the majority of the time.

Level "bounces" with activity - sometimes the damage in my left knee spikes to a 10 and there are peripheral neuropathic "sting-burn" in the lateral center of the left thigh and lateral top of my right. Pain is NOT being managed, although 600mg of Lyrica allows me to sleep usually unabated, sometimes with 150mg of diphenhydramine in addition. Days start with 400mg IR Tramadol in one dose - 8 50mg tabs. I have NO other choice.

14. \*

What kind of pain are you experiencing?

Answer	0%	100%	Number of Response(s)	Response Ratio
Burning			67	85.8 %
Stabbing			55	70.5 %
Aching			57	73.0 %
Cold			43	55.1 %
Tingling			50	64.1 %
Other			24	30.7 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

Other (24 Responses)

Answer
piercing
zinging electrical like a cattle prod or electric fence
aching
dry skin, discoloration, feels like a toothache. hard to describe
black skin coloring sometimes
some loss of strength and mobility
Cramping / piercing pain
twitching
swelling
prickly
numbness
throbbing
numbness
numbness
phantom limb pain
cramping
muscles feel like they tighten around my leg
Sore, Cramping
numbness
spasms, twitching
hot.

numbing
stinging
muscle spasms

**15. \*** Did you apply for a service-connected disability rating?

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			33	42.3 %
No			45	57.6 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

**Veteran with CRPS (46 Responses)**

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			28	60.8 %
No			18	39.1 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

**16. \*** Did you receive a rating?

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			28	35.8 %
No			11	14.1 %
Not applicable			39	50.0 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

**Veteran with CRPS (46 Responses)**

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			23	50.0 %
No			5	10.8 %
Not applicable			18	39.1 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

17. \*

If yes, what percentage?

1 = Not applicable, 2 = 10%, 3 = 20%, 4 = 30%, 5 = 40%, 6 = 50%, 7 = 60%, 8 = 70%, 9 = 80%, 10 = 90%, 11 = 100%

1	2	3	4	5	6	7	8	9	10	11	Number of Response(s)	Rating Score*
											73	3.6

\*The Rating Score is the weighted average calculated by dividing the sum of all weighted ratings by the number of total responses.

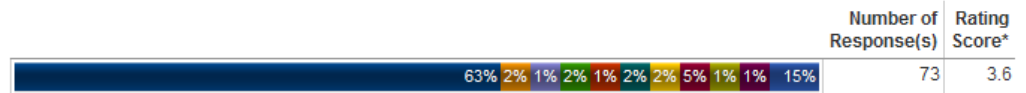
Details

1 = Not applicable, 2 = 10%, 3 = 20%, 4 = 30%, 5 = 40%, 6 = 50%, 7 = 60%, 8 = 70%, 9 = 80%, 10 = 90%, 11 = 100%

1	2	3	4	5	6	7	8	9	10	11
46 (63%)	2 (2%)	1 (1%)	2 (2%)	1 (1%)	2 (2%)	2 (2%)	4 (5%)	1 (1%)	1 (1%)	11 (15%)



Hold the mouse over each color of the bar to see the number of respondents.



18. How long did this process take?

33 Responses

Answer
Three years
since 1982 hope info RSDSA.org and TMJ research about 2 years from the time I first filed
6 years
just about three years
over 2 years
almost 2 years
Don't remember.
about 2 years
almost 4 years
Three years.
3 years
About 3 years.
N/A
A couple of months.
Less than a year. Had the help of Congressmen
He said years
2 years
I think it was a year
A few months
I was diagnosed with 3 months.
3 years and many tests and evals

Around 2 years
?
7 years
about 1 year
couple months
On-Going currently 3 years
9 months: rating is NOT based on CRPS
n/a
YEARS! On-going.
I started with 10% and am now at 40%. % years
still waiting on the rating board to finish

**19. \*** Are you currently on disability because of your CRPS?



Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			36	46.1 %
No			41	52.5 %
No Response(s)			1	1.2 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

**Comments (35 Responses)**




Answer
I use a wheelchair for mobility. I have right side paralysis.
You can try to do this but they do not believe this is a disease or whatever and will turn you down everytime.
I have applied for disability 3 times, and have been denied all 3 times.
Am trying to work again, but was on disability
on SSDI multiple. VA don't accept because was not discharged for arm pregnant
Despite records from a half dozen doctors we have been denied disability based on one non VA doctor who spent less than 15 minutes on an exam with no physical interaction or tests.
My rating is for PTSD. I know that PTSD is a cause of pain. I have felt it, indeed lived it and thought about it every day for 40 years now
I am on disability for these injuries and their aftermath. I also get migraines from the nerve injuries in my back. It's been fractured 5 times. I am not getting a rating for RSD from the VA
I recieve my doctors appointments and my medication thru workmans comp settlement. I'm covered for life on doctors and meds.
n/a
I was denied the first trial and now have finally received help a month ago.
I am still active duty
combination of PTSD and CRPS give me unemployability 100% rating.
40% for the missing parts and 10% kidney stones
I am 100% VA and fully disabled SSA.
I am as far as my doctor's are concerned. But workman's compensation is different. They have not paid me any compensation on lost wages. They are just now working on paying some of my out of pocket. Yet, because of all the BS I will be not reimburse for a lot. It is a long story. Yet. all the bills are due to my injury and sufficient medical documentation to back it up.
I was out of work for almost 3 years, but now they work with my condition
Complete and Permanent

social security took 5 months and I have a pacer so combined it was not hard to get
I received a monthly check and am unemployable.
I was a welder before the accident, but with the RSD in three out of four limbs it's hard to do any job.
my total disability for the VA is 50%. Still fighting for 100%
No they are fighting me tooth a nail for 100% ,for the CRPS disability rating
Social Security Disability
I am on VA disability and have filed for SSD which I have been waiting 4 years for now.
Have turned VA appeal over to U.S. Congressman Brett Guthrie
Have VA disability as well as Social Security Disability
partly other conditions too
recieving social security disability
Since being back I am working with the VA as the original physician to see me for my initial determination refused to acknowledge the CRPS and we have been fighting to get it corrected since March 2007.
I am on disability because of: Dx L4/L5-S1 DDD, DVT, Tibial Plateau break - left, 2 - back to back, Full Saddle PEs.
My wife was just approved for SS disability.
I'm on disability for the pain resulting from the numerous injuries I suffered, including the RSD.
Haven't applied yet
My disability is for back surgery.

#### Veteran with CRPS (46 Responses)

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			24	52.1 %
No			22	47.8 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>46</b>	<b>100%</b>

20. \* It is okay to contact me regarding my experiences.

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			68	87.1 %
No			9	11.5 %
No Response(s)			1	1.2 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

21. \* When visiting the RSDSA website or contacting the RSDSA offices, what kind of information are you looking for?

Answer	0%	100%	Number of Response(s)	Response Ratio
About CRPS			49	62.8 %
Awareness and Advocacy Initiatives			33	42.3 %
Diagnosis and Treatment Criteria/Guidelines			55	70.5 %
Disability Resources			34	43.5 %
Events and Fundraisers			19	24.3 %
Disability Resources			29	37.1 %
Financial Resources			21	26.9 %
Publications			34	43.5 %
Research Updates			56	71.7 %
Resources specifically for Veterans and Military Personnel			22	28.2 %
RSDSA Membership			16	20.5 %
RSDSA News			37	47.4 %
Stories of Hope			27	34.6 %
Youth			2	2.5 %
Other			5	6.4 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

**Other (5 Responses)**

Answer
RELIEF with ez items Theracane
Answers and guidance support
IT note: you have two "Disability Resources" in the check box list. when a red flag is up for a certain prescription.

22. How can RSDSA help you?

Active Duty Member of the Military with CRPS (1/2)

Answer
Help me find a lawyer. All I want is my lost wages and all of my out of pocket expenses reimbursed. Get my full disability. And to see if there is a class action suit that we can help all the other's that were treated wrongfully. No one should have to go through so much BS to get their medical treatment asap after they have been injured on the job. We were all under workman's compensation, told we had to do the block's, got the surgery and now we are all in a lot of pain. One dead, one permanently paralyzed, one on a wheelchair, and the rest are trying to live life to the fullest. Not only ourselves are going through pain and suffering, but our loved ones and family.

Veteran with CRPS (30/46)

<b>Answer</b>
Advance an initiative to force the Veterans Administration to recognize and provided disability for Veterans with RSD.
Thanks keep all of us in your prayers. and the NIH connect with TMJ and their NIH and govt contacts. PAIN IS PAIN APF too. great IFFGD too work with all the complementary medicine peoople . Massage therapist janet at Natural Medicine Lakeland fL tell me of advance conference on Somato of Brain and massage. in Sarasoto I think Jan.
By bringing further awareness to those among the medical profession and continue to support research to find relief for us that try to live through the pain. Many of my fellow veterans have given up the fight, no longer able to wait for a day of peace and serenity. I have come close to joining their ranks on several occasions and I hope that RSDSA can bring a successful treatment in order to save today's veterans from the agony suffered by those who have gone before.
Not much it seems at this time. I need to work, and so far I have been able to just deal with the pretty much constant tingling and burning sensation. Medications really have not worked, and if they do take the edge off, the side effects seem worse.
Continue what you are doing.
Provide information on studies, give advice on how to contact the VA,
Really don't know. I surf the web for information on my condition. People really don't see how bad i hurt because i hide it. I work no matter what because i have to. I can't live on \$500 a month from Social Security. Workmans Comp hassels me sometimes by making get my medicine thru them instead of my doctor. They tried pulling some really weak, crappy generic meds on med that didn't work. They try to buy me out every now and then, but don't want to give me any disent amount of money. This is something that I'm learning to live with, but it's different from day to day and storms make it unbearable.
Provide supporting information on the disabling effects of long term pain, being tired, out of sorts, sensitive to touch, depression.
It has already! When my wife and I were looking for information about RSD in 1993-4, RSDSA was a beam of sunlight in a dark landscape. We didn't get much information from the doctors, or it was presented so rapidly we didn't have time to absorb the message. RSDSA gave us hope for treatments, community and the feeling that I was not alone with all these symptoms which some "Dr's" were suggesting were all in my head. Please keep providing the vital information on the web site and in the newsletters, so that we can get the word out about this nasty disease.
Is there help for individuals who have lost their job and don't have health insurance to be able to continue to get the treatment that they need to keep their RSD under control. I have not been able to be treated for my RSD for over a year now and I have some days when the pain is so bad that I can't even see straight and over the counter meds do not help.
Help get training to physicians/technicians so they are not afraid of treating to prevent over/under medication prescriptions
Simply put, keep doing what you're doing! RSDSA was absolutely essential following my diagnosis, the acceptance phase, and the "living with it" phase. You guys help so many of us each and every day! I don't know what I would have done without you at the beginning. In particular, Keith took the time to write to me individually, a message I keep just in case. Your organization has grown a lot since I became a member. Amazingly, now you are having an impact on our Government --- regularly! That's a far cry from a little informational website that I remember. How can you help me? Keep on truckin' dudes! You're marvelous!
Give the VA more awareness and diagostic tools to give proper treatment.
Just keep helping others fight this terrible disorder. I don't know if there is a forum on the website but that would be great if there was one.
I don't know I have tried everything and it only gets worse.
Not sure.
The information will help me and others to better understand this dreaded monster.
Help the medical field be more aware that we as a people with disability of RSD are not faking. I would also like to get some help with my disability.
More in the box, or out of the box treatments, where they are, what they are, etc. What about the treatments in Philadelphia, surgery in D.C.,Bariatric in Spokane, Florida, California, Hot Springs and any other treatments, whether valid or not.
What you all are doing is great and getting the awareness out there , hopefully I will be able to help in some way ,

somewhere down the road
Get support groups for different areas or a website dedicated to crps patients with specific injuries.
Just keep me updated with emails, I love getting the info right as it comes out. Keep the collection of information going because I love being able to search for specific treatments and their effectiveness at will. Keep pushing for not only legislation, but for studies and funding which all help each and every single one of us suffering from CRPS. Thanks for doing what you do.....
I believe I am entitled to compensation from the VA for negligence and incompetence, in that they never sent me to a neurologist or pain clinic, in six (6) years.
Continue to provide up to date info, hope and a caring staff who are available to ask question of.
you have always been able to help me or lead in the right direction. I am so very pleased to hear someone is finally educating the va.
being able to form or locate support group in local area.
I am looking for resources and presidence to present to the VA to help get them to change my diagnosis and disability for CRPS. I am currently unable to work and have little (10%) use of my right (primary) arm. Any financial resources would be helpful as well.
Lobby Medicare to approve Lyrica to treat RSD, better yet, lobby the federal government to allow individuals the right to select the medication that works best for them.
I enjoy the newsletters and I'm interested in anything related to my problem.
i usually answer any questions that are in my area of experience (someone asked about a good doctor in my area once). also like to keep an eye out because i am on alot of meds that are just fda released and i want to know if there is any kind of recall. not had that happen yet thank god. also look for stories of hope to help me gain strength to carry on forward. use the website to refer family and friends to go visit so they may learn what i am going through and what the processes are

Family member, friend, or colleague of a Veteran with CRPS (6/9)



<b>Answer</b>
It gives you some hope but I have given up. I fought for over 6 years and I have no more fight in me. I just read it and hope that no one has to go through what I have.
Keep working to find a cure.
Please educate the doctors at va because they have no clue about rsd nor how to treat va vets with rsd
By keeping up with the latest technology and being understanding.
The VA won't help as far as his wheelchair. Medicare ended up getting it for him. They won't put him a lift in the van because they didn't give him the wheelchair since they said it might keep him from walking. They won't fix the house with ramps or anything. They do however send someone to give him a bath and they someone to help with the housecleaning and watch him to I can get out for a few hours.
Learning how to manage RSDSA.

Other (11/21)

<b>Answer</b>
Help me find a support group in my local area.
information, awareness, support
I need to find a physician in my area that is informed about this condition. Perhaps that can suggest other drug therapy. Something anything for help
Make more doctors aware of this disease. My feet are peeling as a result of this disease and when I go to see a different dr that is not aware of this disease they seem to think that I don't take very good care of myself hygiene wise. It is very embarrassing.
Find a good program such as Mayo Clinic has. Find a cure or effective treatment for CRPS. Mobility assistance. The best approach. A job where I can use my expertise and knowledge. Some means by internet to let those suffering with CRPS obtain the best nutritional supplements that I've found. What effect does smoking have on CRPS. Is it a risk factor? Does CRPS become worse with smoking? How can I educate doctors by presenting myself as a study case? How can I participate in research?

I have an interest in working, to some degree, for the VA hospital in Gainesville or Lake City.
Information about the disease. I find it disheartening that so many do not understand this disease or believe it is even a debilitating disease.
I don't that they can I always feel that maybe I can help someone else. Not that you couldn't you probably could don't take me wrong I'm sorry. I'm just been through a lot that is all.
Just keep us informed as you're already doing.
Do not know....
I would like to know if it will ever go away
Please find other treatments and perhaps a cure. It is killing me to watch my wife in pain!

**23. \*** Are you a member of RSDSA? (More information on membership: <http://www.rsd.org/1/membership/index.html>)

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			40	51.2 %
No			38	48.7 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>78</b>	<b>100%</b>

**24. Additional Comments or Suggestions:**

**24 Responses**

Answer
RSDA helped me understand what was happening to my body. This website led me to find the appropriate medical doctors and subsequently, proper care.
Thank you for your time and dedication. Few people understand this horrific disease and the level of pain we endure. In the early stages many of us are confused and feel abandoned by the medical professionals. I have come to realize that the lack of adequate therapy and treatment caused my mobility problems. Recent attacks have been overcome with physical therapy and endurance ... thanks to the information acquired here.
Info RSD from NORD family conference adults. believe 1991 celebrated a honeymoon with 2nd husband . I'd love to see more of a family retreat so assist the children of affected adult. Maybe I'd still be married and the Kids wouldn't be so bitter as adults and passing on the maladaptive chronic pain behavior to grandchildren. repeat generations. father WWII vet. stoic. etc Best advice he gave me when forced to go home to live was you have bursitis . use it or lose it. so the peaceful sitting in the garden crying over all my losses helped . but severe flairups till I rehash what I'm not letting go and recognize tiggers such as the generator/refridgerator behind me to remember to breathe in GOD's Light and Love Release to JESUS and let the Holy Spirit take care of things and relax ..... Have a Blessed Season. The reason I chose to volunteer to assist the abandoned non accepted hostages in IRAN because I identified with being Abandoned and not accepted by family friends life growing up.poor
I don't remember if I have joined RSDSA or not Memory issues arise with pain issues, unfortunately. If I could somehow help find hope for others, I would indeed like to be part of your organization Also, I hope that in some small way my survey helps the thousands of largely misunderstood veterans who seek relief for their legacy of pain. Thank you
Thank you for getting the word out. RSD is hell!
Thank you for looking into the Veterans experience with CRPS.
If you can help just one person that would be wonderful. I wouldn't wish this on my worst enemy. I'm thankful i have family and friends that get me through my roughest times.
Podiatrist first commented on this and referred me to rheumatology who made the diagnosis. I will know more from the VA by next month.

<p>Help for unemployed and uninsured individuals who have RSD and need treatment so they don't have to suffer without any relief from the pain.</p>
<p>More awareness of physicians on the diagnosis and treatment of RSD. Instead of being told that the pain is your imagination and not real.</p>
<p>Warning to RSD patients that a sympathectomy reduces your chances of receiving the common treatments for RSD recommended by most physicians. Had I know that before hand, I would not have had the surgery. I was just looking for a way that I wouldn't have to get a nerve block once a week and try to get off of pain meds.</p>
<p>Your organization and all the links provided have been a God-send to me. We have read all the cases and all presented so far. To know more is to be comforted that I am not the only one suffering with CRPS. I only wish doctors would be required to read the websites.</p> <p>Thank you for all you do, Cyndy</p>
<p>I did not know there was a special veteran section of RSDA. Would it be possible to link it from the VA website? Veterans - especially younger ones - have a harder time adapting to disability. I have trouble finding suggestions for activities to help with CRPS, since I have previously been very active. I would like to see comments or suggestions on alternative activities to stay or get back in shape, while also keeping my condition from deteriorating worse. I have been able to stay out of a wheelchair, but it has not been easy, as I am constantly re-learning how to exercise.</p>
<p>Thank you for all that you have done and what will come in the future. What you do does matter Thank you.</p>
<p>saturday is my only free time I work with a soup kitchen and people through the week that need some help and I love it. I talk to people about the Lord he is the reason I able to do the things I do. Sad shame people can't see that. Amy Reese Have you asked Jesus in your heart Jesus said no man can see the Father except to go through him first. You have to admit your sins, tell him your sorry change your ways and start reading his word. If you believe you will be saved. It's an honor to work for the most High a true Honor. Tell your Pastor and then get baptised Amen and Amen</p>
<p>Thanks for listening. This is another in a long line of excellent ideas. My check really is in the mail for current membership. Hugh Parker</p>
<p>I wish you all had an office here on Guam, or an agent that comes to Guam to represent us people.</p>
<p>Just take each day as it comes and deal with it</p>
<p>They military needs to help more and have better treatment options.</p>
<p>help!!!</p>
<p>I just want to Thank everyone at RSDSA for being there to help others who are suffering with this Disease.</p>
<p>Thank you for listening but most of all thank you for understanding.</p>
<p>Member of Rocky Mountain RSDSA</p>
<p>Are you saying that duty overseas is a major cause of CRPS? I didn't realize our military service was related. Thank you.</p>
<p>am on very limited income and cannot afford membership.</p>
<p>Why should membership matter? Or is this really about money? If it is about money and not helping the VET, do not bother calling me - "the turnip" truck is back there a ways."</p>
<p>i think i am a member of the website i have been visiting it several times a week for the last 2 years or when i was let known about the website from a nurse while i was in the hospital getting another surgery</p>