About 15 years ago, I developed an interest in the use of Ketamine in my outpatient pain clinic. This came from my use of this agent for animal experiments in my neuropharmacology training in the late 1970s and the knowledge that it was very likely a safe agent to use in sub-anesthetic doses in humans. As I have a largely pain and headache practice, we were always looking for medications that would reduce the horrible burning pain and allodynia suffered by my patients with CRPS.

Our initial data with this agent, which blocks very specifically the NMDA-type glutamate receptors at sub-anesthetic doses wasn’t shown until 2008 for treating CRPS and other painful conditions. While we are not set up to do the longer treatment protocols that are offered by Dr. Schwartzman and his colleagues in Philadelphia, we have found that IV Ketamine, in sub-anesthetic doses, infused over 3-5 days can be dramatically helpful in reducing the burning pain suffered by these patients. I am of the opinion that it may not be so much the dose of Ketamine but rather the time of infusion that matters greatly in its success. We treat patients from all over the country who have experienced as much as a week or two of diminished burning pain with as few as 3-4 days of IV treatment.

We have also been treating patients recently who are referred from medical schools around the country (and even self-referred) for IV Ketamine treatment for treatment-resistant depression and anxiety. This is a whole new chapter on the use of IV Ketamine, so stay tuned! In addition, we have arguably the largest database of IV Ketamine treatment for migraines and other types of headaches.

IV Lidocaine, as well as IV Propofol, can also be used successfully to treat neuropathic pain syndromes, with or without IV Ketamine. Sometimes using two agents with different mechanisms of action can be better than one agent. It’s all about helping the patient have a less severe pain syndrome.
Audrey Johns Shares Her Nerve Pain Smoothie Recipes
By: Audrey Johns

More and more we’re hearing miracle stories of people curing themselves with food. Men and women curing cancer and diabetes, all just by changing how they ate. As a journalist with CRPS/RSD I had to believe I could find nerve pain relief with food and that is what I’m setting out to do. ~ Audre Johns

Below are smoothie recipes packed with Vitamin C, Omega 3 and B12 that Audrey Johns shared with RSDSA Community Update. For both fruit smoothie recipes, add all the ingredients into the blender and mix until smooth, adding water to achieve the desired consistency.

Apricot/Orange Smoothie - add an apricot, an orange, 1 cup spinach and 2 tablespoons ground flax seed.

Orange/Strawberry Smoothie - add an orange, 6 strawberries, 1 cup spinach and 2 tablespoons ground flax seed.

To read more about Audrey Johns, a journalist and celebrity chef with CRPS visit her at http://www.LoseWeightbyEating.com.

Here At Last: Family Summer Camp for Pediatric Pain Patients — Free of Charge!
The Coalition Against Pediatric Pain (TCAPP), RSDSA, and the US Pain Foundation have partnered with The Center for Courageous Kids in Kentucky and have pooled all of our resources to create a camp for kids in pain. This will be a family camp that will take place at The Center for Courageous Kids in Scottsville, Kentucky from July 14-17th and is free of charge. It will be a time for families and kids who deal with daily pain to kick up their heels and have fun in a safe, accepting environment!

To learn more about the camp location and what they have to offer, please visit The Center for Courageous Kids website at: http://www.tcapp.org/tcapp-news/2014/11/5/here-at-last-family-summer-camp-for-pediatric-pain-patients-free-of-charge.

To apply for the pediatric pain family camp, please follow the following steps:

**Step One:** Complete the application on-line by clicking here: Pediatric Pain On-Line Camp Application

**Step Two:** Print out the application, sign it, have your physician sign it and mail it in to The Center for Courageous Kids.

**Other Option:** To print the application and fill it out by hand, click here: Print Out PDF On-Line Camp Application. **All applications will be processed by The Center for Courageous Kids and campers/families will be accepted based on time of application, lodging requirements, and room availability.**

TCAPP, RSDSA, and The US Pain Foundation realize that finances are tight for most families dealing with pediatric pain and transportation to the camp may be difficult. We are all working together to fundraise and provide traveling stipends for those who need them most. More will come regarding this in the future. In the meantime, we hope we have given you enough advance notice to start saving or to fundraise in your community for travel expenses to this otherwise free camp.

We anticipate that this will be a great experience and an exciting time for everyone!! **Let’s have some fun!!! Hope to see you all there!!!** A huge thank you to The Center for Courageous Kids, RSDSA and the US Pain Foundation for helping make TCAPP’s dream come true and be able to offer a camp for kids in chronic pain.
A BIG Thanks to Everyone Who Took Part in CRPS Events Around the Country this Year!

It was a very busy fall in the RSDSA family! On October 25, 2014, RSDSA hosted the Bounty of Hope 30th Anniversary Gala in Princeton, New Jersey. It was an amazing evening that helped raise more than $70,000 for programs that help people with CRPS live more fulfilling lives. Everyone who joined us had a wonderful time using the complimentary photo booth, bidding on exciting silent auction items and enjoying the live DJ playing classic and current hits.

In September, Dr. Philip Getson, Dawn Hesser and a great committee of wonderful people in the New Jersey area put together the Annual Walk for Awareness in Cooper River Park in Pennsauken, New Jersey. More than 400 people joined us for this high-energy event and Dr. Getson and his team raised more than $17,000 for RSDSA programs.

Sara Shanley, a young teen with CRPS along with her parents Tom and Patti organized a walk and a silent auction in Lockport, NY. The first-time event was an incredible success. The silent auction was comprised of over two hundred items! Sponsors’ names were listed on placards along the walk route. It truly was a community event, which raised more than $7,500 to support RSDSA’s educational initiatives.

Despite a cold and rainy day, the RSDSA community came together in Lincroft, New Jersey at the First Annual Walk of Hope for a Cure. Erynn Carrol and her team raised more than $3,000 for RSDSA.

Erica Hayashida who has lived with CRPS for seven years, organized a CRPS Awareness event, Freeze the Burn on November 1 at the Billings Montana Zoo to benefit RSDSA. Walkers and runners were encouraged to wear super hero costumes. The walk raised $6,000 to support RSDSA programs and initiatives.

Also in November, Beth Stillitano and her family along with Carolyn Laraway hosted the Annual Fight the Flame 5k in Charlotte, NC. It was an incredible day with hundreds of people joining us from all along the East Coast. Due to the efforts of everyone involved, the race raised more than $25,000 for CRPS Research! We look forward to next year’s walk/run on November 1, 2015.

We wish to thank everyone across the country who has helped support and bring awareness to the CRPS community through their local events.

Thank You So Much for Your Continued Support of RSDSA!

We could not do it without you!
Health care providers often encounter patients taking opioid analgesics from previous providers. In people with CRPS, short-acting opioids were likely initiated following an initial insult such as a fracture, burn, or surgery. Then, when the person’s pain complaints failed to improve in an expected timeframe, the treating provider may have begun to suspect CRPS. Opioids may have been prescribed along with a variety of neuroadjuvants, often with less-than-satisfactory results.

Unfortunately, while opioids have many positive qualities for patients with normal acute-injury pain (e.g. relative efficacy, relative lack of toxicity), opioids are know for activating changes in glial cells in the central nervous system. Those glial cells release inflammatory cytokines, leading to central sensitization. Thus, in the case of CRPS, the opioids prescribed may actually make the problem worse.

While some people with early-stage CRPS describe significant relief from opioids in terms of helping them to tolerate the rigors of occupational and physical therapy, it is not always the case. As a result, a provider who is asked to take over the management of a person with CRPS has to make a clinical decision regarding whether or not the individual patient seems willing to take an active role in the ongoing management of the disease. If so, continuing opioid medication may be reasonable. If not, discontinuation of opioids is reasonable.

The goal of pain management should be functional improvement, not simply analgesia. Patients who are taking opioids should be asked to describe, in detail, some specific functions they are able to perform with the opioid treatment that they were not able to perform without opioid treatment. This functional improvement (or the lack thereof) should be clearly documented.

Another reasonable reason for discontinuation of opioids is failure of a person to maintain the security of the medication. A person who reports medication as lost or stolen may be given a second chance, depending on the circumstances that brought them to you in the first place, but repeated instances of inappropriate handling of medication cannot be overlooked by the prescriber. Evidence of illicit activity (e.g. taking illegal drugs such as cocaine, heroin, marijuana, illegally-obtained benzodiazepines, etc.) may also lead a prescriber to decide to discontinue opioid analgesic management.

On a more positive note, some promising results have been seen in recent years with regard to the use of low-dose naltrexone (LDN) in the treatment of CRPS, as well as in other conditions long-understood to be the result of immune modulation (e.g. rheumatoid arthritis, multiple sclerosis, Crohn’s disease). If a provider finds it reasonable to have the person try LDN (which is an off-label use), that provider will need to taper the patient off opioids first.

With routine use, opioid medications produce physical dependence. However, opioids are not life-sustaining. As a result, there is no person taking opioid medication who cannot be tapered off opioid medication. It does not necessarily mean it will be easy or pleasant for the individual, but it is possible. Nonetheless, the prescriber must take into account extenuating circumstances that may require the tapering process to be put “on hold” (e.g. pregnancy of the opioid-dependent patient, since the stress of the tapering process may precipitate miscarriage).
Countless different protocols exist for “weaning” of opioids, but one widely regarded as safe is to calculate the total opioid daily dose in terms of “morphine equivalent dose,” or MED, and reduce the dose taken by 10% of that initial MED value each week. This results in a 10-week taper, more than gentle enough for the overwhelming majority of people taking opioid analgesics.

For instance, a person taking immediate-release oxycodone 30mg QID is taking 180mg MED. Using the 10% protocol would have the prescriber reducing the daily dose by about 18mg MED, on a weekly basis. Since there is no oxycodone preparation that exactly equals 18mg MED, the next best option would be a 15mg oxycodone dose. The person would be instructed to break the 30mg tabs in half, and take 3.5 doses per day for a week, 3 doses per day for a week, etc.

The calculation of MED is rather straightforward, and the calculation of a 10% tapering protocol is not much more complicated. In most cases, the most difficult part of opioid discontinuation is negotiating the “emotional fallout” of the process, particularly if it is being done as a result of aberrant behaviors. The person undergoing the taper may be angry, accuse the prescriber of indifference, may make threats of legal action, and so forth. The prescriber should take the knowledge of the opioid recipient into account in deciding whether to have the person come back to the office to pick up a weekly tapering prescription, or if a single prescription with tapering instructions would suffice.

In summary, the goal of all treatments for CRPS should be functional improvement. Any treatment that results in improved self-sufficiency and independence is worth considering. No one treatment has been found to be helpful in every single case of CRPS, but by explaining the risks and benefits of each treatment to each person who presents with CRPS signs and symptoms, the provider stands a good chance of winning each person’s respect.

We Have an Exciting New Opportunity to Support Others with CRPS!

In 2014, RSDSA celebrated 30 years of serving people affected by CRPS. Founded in 1984 to provide support, education and hope to people living with CRPS and their families, RSDSA continues to fulfill its mission. This year, as we celebrate our first 30 years, we not only reflect upon our rich history, but lay the foundation for a strong future as well.

Thank you for helping thousands of people with CRPS! Without your generous support, we would not be able to provide the following: two conferences in 2014 for people with CRPS, their families and caretakers; research grants that are exploring new treatments; and dispense financial assistance to those in serious need.

You give so much throughout the year, and we here at RSDSA appreciate all that you do every day. We also understand that people are often seeking a way to give that holds personal meaning. To that end, RSDSA is excited this year to offer our community for the first time... The RSDSA Gift Opportunity Catalog!

We hope that you will take this opportunity to visit http://www.rsds.org/pdfsall/2014-Year-end-gift-catalog.pdf to review the options we have available and help all those affected by CRPS.

We thank you for choosing RSDSA! With your help, we will be here for your friends, family and neighbors who live with CRPS when they need us most.