

IN RARE FORM



Support RSDSA's End of Year Appeal

For the second year in a row, the pandemic has impacted all our lives. Some of us have lost loved ones, some have lost their livelihoods, still others have lost their good health. Many businesses, including non-profits, have had to close their doors. We were fortunate here at RSDSA. We were able to continue serving those who suffer from unimaginable pain, for whom the isolation imposed by COVID-19 is particularly devastating. Your generosity made that possible.

Your donation enabled us to expand our online presence during the pandemic. By helping us raise awareness of new pain management techniques, you provided hope and critical information to the community plagued by constant pain, a community which too often considers suicide their only option. Last year, we lost 244 individuals that way. At each of our presentations, over 1,000 CRPS Warriors have taken the opportunity to become informed and to engage with others. With your help, we will continue providing information and support to our community. Together, we can work to reduce that staggering statistic.

Your support gives hope. You help provide a place where one can search for information on the latest research and treatments. Your contribution enables the community to share experiences and connect with others.

Finally, you helped us publish the 5th edition of CRPS: *Treatment Guidelines* (last updated in 2013) an invaluable resource for both the medical community and those with CRPS.

None of this is possible without you! Please consider making a gift to our end of the year appeal [here](#). TOGETHER WE CAN MAKE A DIFFERENCE!

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Take Note of These Patient Assistance Programs Ahead of 2022

There are a variety of patient assistance programs available and we have compiled a list of some of the programs as well as links to their websites and applications. Some of the programs may have deadlines or very specific requirements. Please read through them to find the ones that best fit your needs. The financial aid programs listed are managed by different organizations and are independent of RSDSA.

National Organization for Rare Disease (NORD)

NORD's patient assistance programs help patients obtain life-saving or life-sustaining medications they could not otherwise afford. These programs provide medication, financial assistance with insurance premiums and co-pays, diagnostic testing assistance, and travel assistance for clinical trials or consultation with disease specialists.

To apply for assistance, you first need to locate the program on their website [here](#) then follow the related contact information. If you do not see a patient assistance program listed that meets your specific need, you can contact NORD's Patient Services Representatives at 1-800-999-6673.

In some cases, NORD offers financial assistance for registration costs for rare disease-specific educational offerings, as well as programs that support patients' health and well-being, such as workshops, nutrition classes and conferences. In addition to assisting with registration fees, the Rare Disease Educational Support Program provides limited financial assistance to patients and caregivers for travel and lodging costs.

For more information and to apply, please contact: rdeducate@rarediseases.org or 860.556.2208.

NORD also has a Rare Caregiver Respite Program. Learn more about the program [here](#).

Partner for Prescription Assistance

Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage obtain the medication they need at low cost or no cost. Their mission is to increase awareness of patient assistance programs and boost enrollment of those who are eligible. You can also find a free or low-cost clinic near your home or workplace. Visit pparx.org for more information.

Chive Charities

Applicants share their story with [Chive Charities](#) by submitting an application and working within their guidelines to raise money for your aid and others. They target three specific causes: rare medical diagnoses, first responders, and veterans. Chive Charities spreads awareness through sharing the personal stories of grit, courage, and never giving up.



Charitable Giving for 2021

The one-time \$300 “deduction”: For the 2020 tax year, individuals who take the standard tax deduction (that is, they’re not eligible to itemize their charitable contributions) may, in addition, take an “above the line” deduction for cash gifts made to qualified charities, up to \$300.

Unlimited charitable deduction for 2020: For those who can itemize their deductions, in 2020 these taxpayers may deduct the entire amount of the cash gifts made to qualifying charities – meaning that these individuals can choose to entirely “zero out” their tax obligation for the year.

Take Part in a CRPS Research Survey

The survey intends to answer research questions that still exist regarding Complex Regional Pain Syndrome (CRPS). These include questions such as ‘Who is more likely to suffer from CRPS?’, ‘Which are the most effective treatments for CRPS?’ and ‘How much does CRPS affect the lives of patients?’

Learn more and take the survey [here](#). While the study is based in the UK, those who do not live in the UK can still participate.

Litigation Update: Why a Life Care Plan is an Invaluable Piece to Your Case

By *Lawrence Krasin, Esq.*

Through hard work and good fortune, I have helped build a large legal practice in New York. Much of our work is composed of case referrals from other attorneys who have seen the results we have produced. More often than not, however, most of these cases that have been sent to us consider only the immediate effect of a catastrophic injury. However, as we have learned through the years, most of the injuries suffered by our clients have impact upon themselves and their families that can effect the rest of their lives. While Workers Compensation or Medicare may provide some assistance, the long term affect of the injury is, sadly, largely ignored.

Many attorneys with smaller practices (and even large ones) will not look behind the numbers, and, unfortunately see a large and immediate payout from an insurance carrier and grab it. Consider, for example, a case we had a few years ago when a solo attorney consulted us on a case they just received where a young construction worker fell through a scaffolding platform in New York and fractured both of his calcaneus (heel) bones which required immediate surgery.

This attorney, a solo practitioner, was offered a fairly large settlement from the construction company before a lawsuit was even initiated. The settlement contemplated his pain and suffering, the amount of time he would be out of work, his out of pocket medical expenses, and the amount of wages that he missed out on (over and above what Workers' Compensation would pay). Most other attorneys, tempted by a large number, and the prospect of settling before a long litigation would have jumped at the chance for a "payday." This short-sighted approach is all too common in the legal industry.

Thankfully for this young man and his family, the attorney consulted with us before accepting any offer. Most insurance companies know that when we litigate a case, we do not simply look at the injuries suffered and the costs incurred today, we look far down the road. For instance: Will this young man be able to return to work? If so, what type of work will he be able to do? What will be the effect of his fractured heels on the way that he walks? What type of therapy will be required for him to make a full recovery? Will he ever have a full recovery? How will this injury affect his future work life expectancy? Will he need future revisional surgery? Has arthritis (common to calcaneal fractures) been considered in his future? When Workers Compensation stops paying our client, what medical bills will he be saddled with? If he settles the case, will Medicare keep paying for his care in the future?

To answer these questions, we need what is known in the industry as a “Life Care Plan” authored by a reputable physician. These plans require a skilled physician’s eye to look at the injuries and forecast not only what resultant injuries the client may suffer in the immediate future, but what the client’s injuries and sequelae will look like in the next ten years, the next twenty years, and for the rest of their lives. We made a vow when we started our firm that we will make sure our clients are taken care of for as long as they need care, and Life Care Plans are designed to make sure that that vow is fulfilled.

Life Care Plans are especially crucial to cases which involve RSD/CPRS especially since the symptoms of this disease are not always immediately apparent. As many readers can attest, the medication required to address the severe pain of one who suffers with RSD/CPRS can be astronomically expensive, and not always covered by medical insurance plans. A Life Care Plan is absolutely essential in cases in which a client develops RSD/CPRS.

The collateral benefit to a Life Care Plan is that it will give an insurance company or a workers compensation carrier a realistic forecast of what “future damages” can amount to. It also signals to the carrier that these are the types of numbers they are likely to see should they decide to further litigate the case, and it typically acts as a disincentive for them to mount a frivolous defense.

In conjunction with a Life Care Plan, we will typically have an economist examine the plan and forecast the amount of money that the Plan calls for in present value and in terms of what the future cost of the care would amount to, given inflation.

Graded Motor Imagery and Memantine Clinical Trial in Australia

We are pleased to announce a graded motor imagery and memantine clinical trial in Australia. To learn more, please visit memoir.neura.edu.au

Memantine is a nmda receptor antagonist as is ketamine. Hopefully, the trial will be successful and it will be another therapeutic option for people with CRPS as an earlier European publication of six cases showed its efficacy [here](#).

CRPS Patient Association Chairman Lee Yong Woo Receives Achievement Award of The Korean Pain Society



Lee Yong Woo, a Chairman of Complex Regional Pain Syndrome (CRPS) Association in Korea, has been selected as the first representative of a patient advocacy group to receive an Achievement Award from the Korean Pain Society.

CRPS Association in Korea commented Chairman Lee will receive the Korean Pain Society's Achievement Award on November 20. The Korean

Pain Society has been selecting and giving awards to individuals or organizations that have contributed to the development of the Society and the health promotion of pain patients.

The official name of the Achievement Award is "Kim Chan Award," and is named after former professor Kim Chan, a top authority in the field of pain treatment. Winners are selected by the Academic Award Steering Committee. The CRPS Association in Korea commented that this is the first time that a non-medical individual has been selected to win the Kim Chan Award.

Chairman Lee was diagnosed with CRPS at UCLA University Hospital in December 2002 and then diagnosed with a disability. He recalled, "At that time, the reality was that there was a lack of even minimal information on this disease, and even a proper treatment or disability diagnosis were also rejected."

Over the past 20 years, Chairman Lee has made a great effort with various organizations and experts to improve awareness of CRPS and patient treatment environment and make CRPS recognized as disability. As a result, according to the government's notice announced in April, CRPS now can be recognized as a disability.

Dr. Sim Woo Seog, the 22nd president of the Korean Pain Society, commented, "The meaning of Kim Chan Award has been further highlighted as a Chairman of CRPS Patient Association, who has made continuous efforts to improve awareness and disability issues of CRPS patients, receives this award." Chairman Lee said, "I would not have received this award without support from many people. With the heart of gratitude, I will continuously do my best to improve guidelines for disability recognition and bring out necessary changes for other patients."

Learn More About The Chronic Illness Advocacy & Awareness Group, Inc.

[The Chronic Illness Advocacy & Awareness Group, Inc.](#) (CIAAG) is a national non-profit organization focused on patient rights and access to medicines. The healthcare system is changing rapidly in response to societal and political pressures. The United States has invested billions into the restructuring of the healthcare system with a large investment into Public-Private-Partnerships to help create and implement strategies that will help solve the nation's most complex public health issues and concerns. As the nation moves forward with new innovative treatments and technologies we must ensure patient rights and civil liberties are preserved.

CIAAG acts as a liaison between the public, lawmakers and other stakeholders. It facilitates productive discussion and provides recommendations to address the knowledge gaps and inconsistencies within the Public-Private-Partnerships that are influencing access to care and healthcare as a whole in America.

They consult with the public and private sector, providing both professional expertise and lived experience. They address issues presented by the use of Public-Private-Partnerships to develop solutions to complex societal problems via the use of pragmatic trials and the biopsychosocial approach to managing population health.

In addition, they provide:

PROFESSIONAL SERVICES such as consulting services, speaking engagement opportunities, media appearances & engagements, policy whitepapers/research, public health policy analysis, and ethical guidance with public-private-partnerships

COMMUNITY SERVICES such as facilitating communication between patients & other stakeholders, amplifying the patient voice, providing curated research in a repository, creating educational materials and webinars. providing mentorship services (including internships), providing patient guidance for filing healthcare related complaints,

In addition, as part of their community work they provide three options for membership.

All members have access to their Monthly meetings. On the first Monday of the month from 1pm to 2pm Eastern they host the [#CIAAGAdvocacyChat](#) where they discuss a variety of topics and host a space for partners and other organizations to share their work and collaborate

They are also starting a second monthly meeting (also on Zoom) called [#CIAAGTrainingDay](#) where they will be educating patients on how to advocate at the state level and provide personalized mentorship for those interested .

CIAAG will also provide information videos on their [YouTube channel](#) where they will present their analysis of public health guidance documents and help people understand them. This will be starting up with an anticipated once a month publication also starting in January 2022.

Treating the Whole Person: Optimizing Wellness Videos Are Now Available



TREATING THE WHOLE PERSON: OPTIMIZING WELLNESS

VIRTUAL CONFERENCE

OCTOBER 25-28



Visit the [RSDSA YouTube Channel](#) to view our videos and presentations from our Treating the Whole Person: Optimizing Wellness virtual conference and be sure to subscribe while you're there!

Support RSDSA by Shopping at Big Y in Connecticut

RSDSA is benefiting from the Big Y's Community Bag Program in January 2022.

For every community shopping bag sold at the Big Y at [150 Boston Post Road in Milford, Connecticut](#), RSDSA, will receive \$1. Help us spread the word to those in the 06460 area!



Finish your holiday shopping on Amazon Smile

Shopping for holiday gifts? Don't forget to begin your shopping at smile.amazon.com so RSDSA can receive 0.5% of your eligible purchases!

Here's how to get set up on Amazon Smile if you have not yet selected a charity:

- Visit smile.amazon.com
- Sign in to Amazon
- Under "Start by picking your charity" type in RSDSA or Reflex Sympathetic Dystrophy Syndrome Association and click search
- We are the only option that will come up so once you see our name click "Select"
- On the next page when it asks "Yes, I understand that I must always start at smile.amazon.com to support Reflex Sympathetic Dystrophy Syndrome Association or (RSDSA)," click the checkbox and then click "Start Shopping"

Here's how to get set up if you have already selected a charity that is not RSDSA

- Visit smile.amazon.com
- Sign in to Amazon
- If you have already selected a charity, on the left-hand side of the main menu you will see "AmazonSmile" with a drop-down arrow. Click it.
- Click the "Change charity" button
- From there, search for RSDSA or Reflex Sympathetic Dystrophy Syndrome Association.
- We are the only option that will come up so once you see our name click "Select."
- You will then see in green "You have changed your charity to Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)."



Host an Event with RSDSA

You can make a difference in the lives of CRPS Warriors and those who love them by helping to raise awareness and funds and by building a community when you host a special event. Help spread the word about CRPS by inviting your friends, family, coworkers and everyone you know to get involved in our mission, events and activities.

You can organize in-person, virtual, or hybrid events. Special events can be opportunities for fun, engagement, and education. Every dollar raised supports RSDSA's mission and makes our work possible. Your donations are gratefully received, impactfully used, and profoundly appreciated.

Need ideas of what to do?

- Be creative. Do it your way; run a beard growing contest, bake cookies, host a pool party with tickets, whatever works for you and your community.
- Fundraise on Facebook: Create a Facebook Fundraiser to celebrate a birthday, milestone or holiday and invite friends and family to donate to your fundraising page.
- Do you have access to a community or outdoor space? Throw a senior prom, game night or pancake breakfast.
- The yard sale is one of our favorites. It raises money and gets rid of stuff at the same time!

We are here to help you plan your own special event. When you're ready, please contact Jeri Krassner, RSDSA's Special Events Coordinator, at jkrassner@rds.org or 917-597-7256.

Give to RSDSA When You Search on Bing

Give with Bing and Microsoft Rewards members have donated \$9 million and counting. Join [here](#) today to make your searches matter. All you have to do is sign up, select RSDSA (Reflex Sympathetic Dystrophy Syndrome Association) and then Search on Bing! When you're signed in, you'll earn points that turn into donations for our organization and mission.

We want your feedback!

Please send any suggestions or upcoming events of interest to our community to info@rds.org and please consider donating at rds.org/donate.

Happy Holidays from all of us at RSDSA!