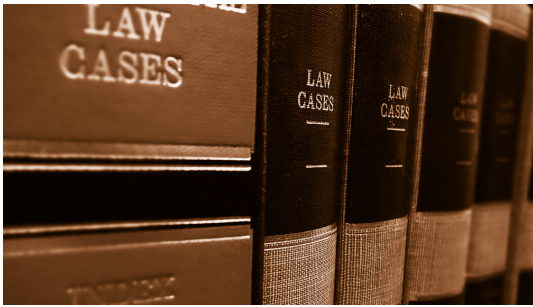


# IN RARE FORM



## Ask The Attorney: To Record or Not Record IMEs

by Bryan D. Pope, Esq

The IME (Independent Medical Examination) is one of the most intimidating exercises someone who is suffering from CRPS may be asked to do during the pendency of litigation on a civil case or during a Workers Compensation claims process. It is natural for the person who is being asked and/or required to attend an IME to want to have some type of record, via audio or video, of the exam. This can serve multiple purposes. First, the patient wants to know what happened during the exam because it's hard to remember what the examiner did/didn't do in the heat of the moment. Second, sometimes if the examiner knows that the exam is being recorded, this will deter bad behavior, like lying about a test that was done/not done or a negative/positive result that impacts the ultimate findings of the IME.

One should assume that the IME doctor is not your friend, and is not being hired to find that you have CRPS....period. Many times your attorney (assuming you have one) will try to make arrangements ahead of time with the Defense attorneys to allow the IME to be audiotaped, or videotaped, or sometimes both. Sometimes, a third party observer (your attorney or a friend or loved one) may be allowed to observe the exam. Again, this provides a strong deterrent against the IME doctor misbehaving.

Consent is the key issue regarding the recording of IMEs. Most states (Texas included) have a "One Party" rule, which is if one party to the recording gives permission/consent, then it is legal to record. Obviously, in a patient/examiner situation, if the patient gives himself/herself permission to record, then it is legal to record the exam. Now, the IME doctor does not have to agree to proceed with the exam if he/she knows they are being recorded, but that is a right that the patient has if they want to proceed with that understanding. There is also no prohibition in the "One

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**HOST AN EVENT WITH  
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Party” states to recording surreptitiously an exam without the doctor knowing, since the “one party” giving consent is the patient.

If you are not in a “One Party” state, then you must get permission from the IME doctor to record the exam, and if that doctor refuses, then you can’t do it....even without their knowledge. Depending on the circumstance of the IME, you might want to have an agreement with the doctor that you are just recording the exam so you will have a record of what you said, what the doctor did, etc. and that you will not use that recording in any legal proceeding.

You do have the legal right to walk away from an IME if the doctor refuses to allow you to record the exam. However, this may negatively impact your litigation or the Workers Compensation claim in which the insurance carrier is requesting an IME. There is a duty of cooperation with the insurance carrier in a Workers Compensation claim and the refusal to attend an IME might result in the denial of the claim or other negative actions. Thus, you may have to weigh how important the recording is versus your continued benefits and medical treatment.

If you have any questions regarding this issue, it is best to consult with an attorney before proceeding on a path that may result in the termination of your benefits or negatively impact your civil litigation case.

## University of Bath Study

The University of Bath is conducting a research project about automatic motor processes. Researchers are looking for people with chronic pain in any part of one arm to take part in their online study.

In this online study, researchers will ask participants some questions about themselves (such as age and gender) before viewing a series of images of objects with handles, like mugs, along with pictures of hands. Participants will be asked to press keys depending on whether the hand that appears is a left or a right hand. The study takes approximately 45 minutes and the responses are anonymous, meaning that the answers cannot be traced to them.

To thank participants for taking part, they will have the option of submitting an email address for entry into a prize draw for an Amazon voucher at the end of the study. The Amazon voucher will be a local equivalent if the winner is not from the UK, or if Amazon doesn’t operate in their country.



**Do you have chronic hand, arm or shoulder pain?**

*We invite you to take part in our online study on automatic motor processes.*

It includes: Questions and a computer task.  
Duration: 45 minutes.  
Compensation: Prize draw for a £50 Amazon voucher.  
Contact: [m.f.espanaandrade@students.uu.nl](mailto:m.f.espanaandrade@students.uu.nl).



## Facebook Live with Elan Schneider, DPT, MSPT, CYT - Thursday, March 31, 2022



Join RSDSA for our next Facebook Live with Elan Schneider, DPT, MSPT, CYT on **Thursday, March 31st at 1:30p Eastern** as he discusses using digital health to target pain related neuroplasticity.

Elan Schneider, DPT, MSPT, CYT, is a physical therapist specializing in neuro-rehabilitation of chronic pain. Dr. Schneider co-founded the Retrain Pain Foundation, a non-profit organization dedicated to pain education, and has created educational content used in pain clinics throughout the world in over 30 languages.

Dr. Schneider is also the co-founder of TrainPain – a digital health company developing novel technology for pain related neuroplasticity. He is optimistic about the future of pain care and is a passionate advocate for public awareness of modern pain science, and its implications on policy, health care systems change and improved patient-centered care

What questions do you have for Dr. Schneider? Send them to us for our Facebook Live on March 31st.

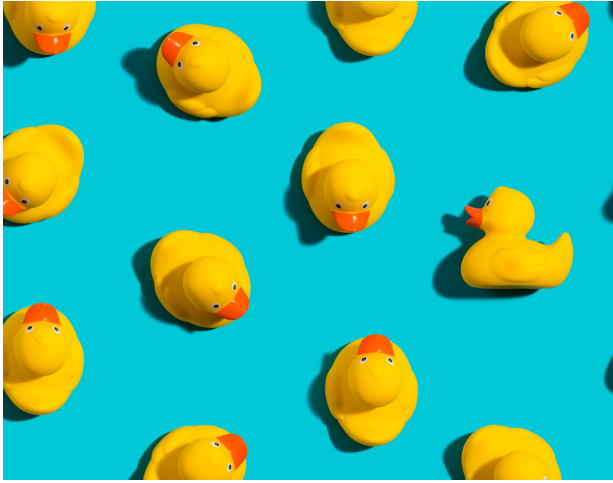
## Dallas Warriors: Attend and Support Walk Strong on Saturday, April 16th

18-year-old Miller Kerr is hosting a CRPS Awareness Walk, Walk Strong, on Saturday, April 16, 2022. The event will begin at 9:30a at Semones Family YMCA (4332 Northaven Road, Dallas, Texas 75229).

Learn more about Miller's journey and how to register/support by clicking [here](#).



## How Can a Rubber Duck Support RSDSA?



The Pawcatuck River Duck Race is happening on Saturday, April 30, 2022 at 1:30p and RSDSA is selling Duck Sponsorship Certificates for \$5 each [here](#) until Friday, April 15, 2022.

Thousands of rubber ducks will participate in the race. Each duck is the exact same size, color, and weight. Judges will preside over the event from various land and water locations. A specially created funnel will ensure that only one duck crosses the finish line at a time.

If the duck that crosses the finish line has the same number that is on your Duck Certificate, you will be the winner of the race!

There are over 90 valuable prizes awarded with the grand prize being a trip for four to Walt Disney World with airfare, hotel accommodations, and park passes or \$2500 in cash! The grand prize winner is responsible for all taxes. Prizes must be picked up within 60 days of winning.

Additional prizes include getaway packages, gym memberships, gift certificates to retailers, restaurants, golf courses, and much more!

**You do not need to be physically present at the event in Rhode Island to win a prize. RSDSA will send your duck certificate to you.**

This event is sponsored by the Ocean Community Chamber of Commerce. RSDSA will receive \$2.85 per duck sold and the Chamber of Commerce will receive \$2.15 per duck sold. We are both non-profits and will both benefit from this event.

RSDSA's proceeds will support programming for our camp for children with chronic pain as well as education and research for individuals and families in the CRPS community.

If you are interested in helping to promote this event by selling Duck Certificates please contact us at [jkrassner@rsds.org](mailto:jkrassner@rsds.org).

## Purchase Tickets to the Connecticut Suns vs. Seattle Storm Game - Friday, June 17, 2022

RSDSA is excited to be teaming up with the Connecticut Suns of the WNBA for a community building fundraiser at their game against the Seattle Storm on Friday, June 17, 2022 at Mohegan Sun Arena in Uncasville, Connecticut.

RSDSA will have a table on the concourse and will be involved in other activities during the game including a raffle.

[Tickets](#) are now available and the arena will have ADA compliant seating available.



## Painting the World One Dandelion At A Time



Join us for another Painting the World event with instructor Kathy Albritton Gustafson of A Broad and a Brush.

- When: Sunday, April 3, 2022 at 2p Eastern
- Where: In the comfort of your own home
- Cost: \$40 price for newcomers. \$25 for repeat attendees.
  - Cost includes the instructor fee & supplies
- **Deadline for registration is March 25, 2022**

Look forward to a new season with a friend by painting a spring scene! United together, we are raising awareness for RSD/CRPS. Please join Instructor Kathy Albritton Gustafson, as we “make the world beautiful one piece of art at a time.”

This event is organized by CRPS Warrior Shannon Leidig and her posse, The Orange Train. For further information or questions, please contact Shannon Leidig at [arialyric@aol.com](mailto:arialyric@aol.com).



# RSDSA's 3rd Annual Virtual CRPS Awareness Walk is Saturday, June 11th, 2022



RSDSA is excited to announce that our 3rd Annual Virtual CRPS Awareness Walk is **Saturday, June 11, 2022**, and registration is open!

In 2021, we had 57 walk teams as well as participants and donors from 34 states and four countries. Our goal was to raise \$50,000, and we surpassed our goal and raised over \$60,000. Thank you to all who participated, registered, & donated.

We hope to make this year more successful with your help by aiming higher and raising our goal to \$75,000. We know that the CRPS community has the strength and dedication to band together and make amazing things happen!

Living with a chronic disease, and constant pain, is daunting to say the least, but to see everyone come together to raise awareness for this rare condition is very touching. Seeing the support from so many reminds CRPS warriors to keep fighting and reminds them that they are not alone!

## Registration Information

- \$25 for adults, \$10 for children ages 5-12
- Register either as an individual or by creating a team
- RSDSA's 3rd Annual Virtual CRPS Awareness Walk t-shirt & medal are included for all United States and Canadian registrants

Together we have the power to do so many wonderful things with the goal of having CRPS Warriors lead better lives. The time to find a cure is NOW, and we can't do that without your help.

## Fundraising Tips to Have a Successful Walk

- Set a fundraising goal, don't be afraid to stretch and put an aspirational goal. You know what you're working towards, and your goal will motivate others to help you!
- Lead by example. Donate to your own page! People are more likely to give if you support your own cause! It can be any amount, but it is your donation that often sets the bar. If you'd like to see your donors give \$25, start with your own \$25 donation.

- On your team page be sure to express why you formed this team and what it means to you.
- Create a personal page, share your own story and experience with CRPS including photos such as pictures from previous walks you may have been involved in.
- Post information on your social media, so people know how to join your team for the Walk or how to donate. People in your social media circles will surprise you in wonderful ways!
- Remind your teammates to fundraise among their friends and family.
- Ask your employer if they have a matching gift program. Many companies will match what you fundraise which doubles the donations.
- Identify your donors. Start the people closest to you. Send emails from your customized Walk page to ask for support. You can also thank your donors and email your team members from your walk dashboard.
- Send an email or text to your family/family friends, college friends, high school friends, Facebook friends, neighbors, and colleagues!
- Share on Facebook about your walk, whether people want to join your team or give a gift. Go to "My Fundraising Tools" Select "Fundraising Dashboard" Then select "Share My Personal Fundraising Page"
- Fundraise on Facebook and Twitter with a personalized message
- Please don't be afraid to ask businesses, companies, and organizations, such as a physical therapy practice, if they are interested in sponsoring the walk.

We look forward to "seeing" you on June 11th. Although we wish we could see all of you fighters in person, the benefit of our virtual walk is that you can have team members from across the country or even around the globe! This allows people freedom to walk on their own schedule and still feel involved in such a wonderful experience!

We have dealt with the burning pain; we have walked through the fire, and it is time to light it up and blaze a trail to our goal of \$75,000!

For more information or questions, please contact Jeri Krassner, Special Events Coordinator, at [jkrassner@rsds.org](mailto:jkrassner@rsds.org) or Kelly Considine, 3rd Annual Virtual CRPS Awareness Walk Chair at [kelly.crpsawareness@gmail.com](mailto:kelly.crpsawareness@gmail.com).



## Virtual Rare Disease Week Recap

Virtual Rare Disease Week on Capitol Hill took place February 22nd through March 2nd. While some felt the virtual events have less of an impact, it opened the door to others who would otherwise have not been able to participate.

RSDSA would like to thank the members of CRPS Patient Protective Task Force who teamed up with RDLA and Everylife Foundation to meet with their Congresspersons and Senators.

This year, some of the focus was diverted by war in the Ukraine. However, the rare disease and CRPS community did have some great successes. Our voices ARE being heard! Kelly Considine, a CRPS Warrior from Connecticut and Chair of our Virtual Walk, was invited to speak at a press conference by her Representative to discuss the challenges lack of accessibility present. At this conference, Sen. Richard Blumenthal (D-CT) and Rep. Jahana Hayes (D-5th district) introduced a bipartisan resolution to reaffirm federal support of the Americans with Disabilities Act.

Sheryl Freed, a CRPS Warrior from New York received agreement from Rep. Lee Zeldin's (R-1st district) Legislative Director, Sarah Talmage, and Rep. Kathleen Rice's (D-4th district) Legislative Assistant, Rachel Colucci to look into amending the SUPPORT for Patients and Communities Act (HR 6) to include exemptions for properly diagnosed rare disease patients and their physicians to allow opiate dosing and refill durations without fear of regulatory sanction or retaliation.

Other good news from Rare Disease Legislative Week includes the efforts by two advocates, one a very determined 14 year old girl, from their meeting with Rep. Mondaire Jones (D-17th district). He agreed to sign on to co-sponsor both the STAT Act and the BENEFIT Act. These are wins for all rare disease patients! Also, RSDSA received an offer to give a presentation about CRPS on one of RDLA's webinars.

There is strength in numbers, and RSDSA would like to extend the invitation for you and your loved ones to join us to make a difference at Rare Disease Week on Capitol Hill next year February 28th through March 3rd, 2023.



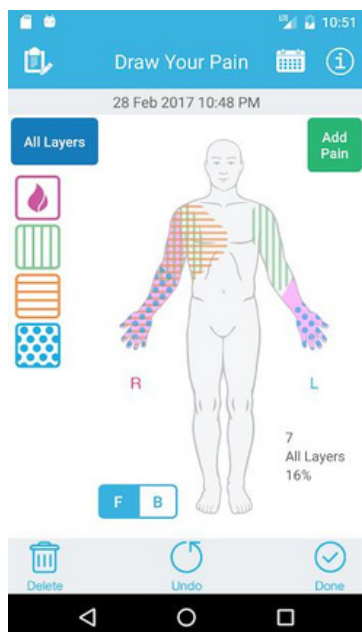
**VIRTUAL RARE DISEASE WEEK ON CAPITOL HILL 2021**



# Guidelines for Health Care Aides, Personal Care Attendants, and Certified Nursing Attendants

With the help of Beth Seickel, RN and suggestions from members of the RSDSA community, RSDSA has [published](#) guidelines for health care aides, personal care attendants, and certified nursing attendants.

## Download the Pain Tracker & Diary App



The Pain Tracker & Diary app by Nanolume® helps users understand and share exactly what they feel every day and keep track of what types of pain your treatments are helping.

Nanolume® developed the Pain Tracker & Diary to help you record the daily textures, intensities, and locations of what you feel, so you and your care team can better understand what you are suffering with and follow how your pain responds to medications and treatments.

Download the app [here on iOS](#) and [here on Android](#) for \$4.

## Interested in Writing for the RSDSA Blog?

We're always looking for Warriors who want to tell the story of their CRPS journey story on the RSDSA blog!

If you're interested in sharing your story with us and fellow Warriors as a form of therapy and/or in order to help those who may be in the same part of their journey as you are, send us an email at [alexisdavis@rds.org](mailto:alexisdavis@rds.org).

# Comedies: Movies and TV Shows Word Search

Please note that words can be found horizontally, vertically, diagonally, and backwards.

The first person to email their completed word search to [jkrassner@rsds.org](mailto:jkrassner@rsds.org) will win a prize!



Seinfeld  
Mrs. Doubtfire  
Family Guy  
Groundhog Day  
Home Alone  
Beetlejuice  
Mom  
Golden Girls  
Good Place  
Pitch Perfect  
Sister Act  
Bridesmaids

Roseanne  
Tootsie  
Friends  
Dumb and Dumber  
Parks and Recreation  
Elf  
Mean Girls  
Big  
I Love Lucy  
MASH  
Big Bang Theory

Legally Blonde  
Caddyshack  
Goldbergs  
Modern Family  
Simpsons  
Office  
Young Sheldon  
Full House  
Clueless  
Connors  
Ted Lasso

## Host an Event with RSDSA

It's a brand-new year, and the perfect time for an event or activity to raise awareness and funds for your community. Any activity can be an opportunity to raise support for advocacy, research, and education. Every dollar makes a difference. You can make a difference!

The opportunities to create, organize, and host are limitless! You can do it your way, whether that's a movie night or a Facebook fundraiser, or join an already established event. You can even turn a birthday, wedding, or other personal celebration into a fundraiser by inviting others to donate on your behalf.

There is no limit to what you can do, even with the pandemic and bans on large gatherings. There are many unique hybrid and virtual events that can raise awareness and money. There are fundraisers you can do as an individual and ones that include your family, your caring circle, your congregation, or your neighbors. We will be there to help you plan and execute any event you like!

Here are just a few fundraising event ideas:

- Zoom Bingo
- Costume contest (or a pet costume contest!)
- Craft night
- Trivia night
- Game night
- Poker run – I admit, I find this one intriguing. Instead of any poker night you can do a poker run. This involves players using various forms of transportation to visit 5-7 locations. At each location, the player draws a card, with the goal to have the best poker hand at the end of the run. It is more luck than skill, but it is a fun time.

## We want your feedback!

Please send any suggestions or upcoming events of interest to our community to [info@rsds.org](mailto:info@rsds.org) and please consider donating at [rsds.org/donate](https://rsds.org/donate).