



### A Message from the President



*Madelaine A. Feldman,  
 CSRO Board President*

When I last wrote this update, it was early March 2020, right before our world seemed to turn upside down from the impact of a global pandemic. The chaos, stress, and isolation we have collectively experienced since then has taken its toll in ways unique to each individual, and lately, I've been focusing on the positive, celebrating the small wins and keeping successes front and center.

CSRO had a few notable successes throughout the past year. We are optimistic about the implications of the Supreme Court verdict last fall in the Rutledge vs. PCMA case. We anticipate this decision will eventually allow state legislation to have an impact on ERISA plans regarding issues such as utilization management and PBM transparency. This September, our State Society Advocacy Conference (SSAC) will include a deeper dive into these possible ramifications of the Rutledge decision. We are also a part of the coalition (ATAP) filing another amicus brief in a related case out of North Dakota.

Collectively, our advocacy against the Most Favored Nation (MFN) Model achieved success in overturning the rule before its January 1 implementation date, while highlighting the continued need for reform around drug pricing. Thank you for speaking out – there were over 748 letters sent to Congress from CSRO advocates across the country. We worked with the Community Oncology Alliance (COA) to put together a tool kit for physicians and patients on this topic which helped spread the word. From a sweeping rule like MFN to state-specific legislation on step therapy and other utilization management bills, your advocacy makes a difference!

As we move through 2021, CSRO continues our advocacy on behalf of the rheumatology community, testifying in states considering new utilization management laws, speaking at a Congressional briefing, meeting with the Centers for Medicare & Medicaid Services (CMS) to encourage responsible rule making, and joining with other national coalitions to amplify our voices. Most recently, we joined the National Community Pharmacist Association (NCPA) in their lawsuit against the federal government regarding DIR fees, and we look forward to having NCPA at our SSAC this September to give us an inside look at its potential impact.

As you can tell, our SSAC will feature both advocacy updates and priorities, as well as important guest speakers representing some of CSRO's partners in our work to advocate for the highest quality of care for patients with rheumatological conditions. I hope you join us in Chicago this year for our first in-person gathering since the start of the pandemic.

See you in September!

Madelaine A. Feldman, MD, FCAR  
 President, CSRO

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## CSRO Joins Fracture Prevention Coalition: Supports Increased Testing Access for Hip-Fracture Prevention

Osteoporosis is a treatable condition with accurate, cost-effective diagnostic tools and inexpensive treatments that work at reducing fractures. However, since 2006, reimbursement rate for DXA testing has been cut by 72%, and office-based providers of this critical screening have declined by 44% since 2008. In 2019 alone, it is estimated that there were 1.65 million patients with undiagnosed and untreated cases of osteoporosis ending in 15,647 avoidable deaths.

CSRO is working to address this nationwide bone health crisis disaster through the support of the Fracture Prevention Coalition. The group has been active in 2020 and 2021 to secure Congressional sponsors of a bill to improve access, and during National Osteoporosis Month in May, federal legislation was filed that set a floor rate of \$98 for reimbursement of DXA tests to ensure more at-risk patients receive it: H.R. 3517, the Increasing Access to Osteoporosis Testing for Medicare Beneficiaries Act of 2021. CSRO will keep you updated on its progress in Congress as we continue through 2021's session.

## CSRO Helped Stall Most Favored-Nation Rule: Awaiting Congress to Act on Drug Pricing Reform



In December 2020, the Center for Medicare and Medicaid Services (CMS) released an interim final rule implementing the "Most Favored Nation" (MFN) pricing scheme for Medicare Part B drugs.

Many in our community were overly concerned with the language that was presented, which left lots of questions unanswered. How would new reimbursement rates be calculated? Which rheumatology drugs would be included? How would biosimilars be treated? Who must participate? What is the bottom line for practices?

Working on behalf of the rheumatology community, CSRO was successful in sharing these concerns with CMS, joining a lawsuit that effectively secured a court ordered injunction and ultimately delayed the rule from being implemented.

The new administration is eager to address drug pricing, but sources say that President Biden plans to let Congress reveal their plans before issuing any new drug pricing demonstrations. Back in April, the House Democrats filed H.R. 3 (*The Elijah E. Cummings Lower Drug Costs Now Act*).

In response, the CSRO issued a letter to Speaker Pelosi's office that expressed concerns that providers who administer medications in their offices may be left underwater. Additionally, the Part B Access for Seniors and Physicians (ASP) Coalition, of which CSRO is a member, shared further concerns for unintended access problems that H.R. 3 establishes.

CSRO's federal government affairs team is actively monitoring this issue and will provide updates to members as they are available. Sign up for CSRO's email newsletter to receive timely notifications about this and other issues.

## Rutledge v. PCMA: Pharmacy Benefit Manager Decision Continues to Create Questions

Last spring, the CSRO took an active role in helping write and submit an amicus brief in support of an Arkansas law that regulates PBMs as part of a case being heard in the United States Supreme Court, where it was being argued that the Arkansas law preempted the Employee Retirement Income Security Act (ERISA).

The Supreme Court ruled 8-0 in favor of Arkansas, which has raised a new question: does this allow expanded oversight to states seeking to regulate health care costs? That question, along with many others, has not been legally answered.

CSRO is attempting to provide some insight by hosting a session on the issue at our 2021 annual State Society Advocacy Conference in Chicago. Jonathan Levitt, co-founder of Frier Levitt, will dive in to the nuances of the case and provide some legal interpretation of the ruling.

Meantime, the PCMA is hoping to get favorable interpretation of the SCOTUS decision by continuing to pursue legal action against a PBM law in North Dakota. The CSRO is supporting North Dakota to uphold the law as the case is heard by the Eighth Circuit Court of Appeals.

### Virtual Gathering a Success!

In an effort to stay connected during a time of isolation, the CSRO hosted a virtual gathering in January where over 100 rheumatologists from across the country came together to visit with colleagues and participate in policy discussions impacting the rheumatology community.

We shared information on the preliminary injunction decision on the Most Favored Nation policy, updates about upcoming state legislation, and what CSRO is doing to help combat the constant payer practice and access issues.

With the success of this first gathering, we plan to come together virtually again in January 2022 - stay tuned for more information!

# Accumulator Programs: Fight Arrives in Congress

Legislation to ban the practice of accumulator adjustment programs has caught fire in the states, which has now led to an attempt to address the issue at the federal level.

These alternative cost-sharing structures prevent the value of co-pay assistance from being applied towards a patient's deductible as an out-of-pocket expense. In the past, once the value of a patient's co-pay assistance was depleted, a patient's deductible had been met, ensuring they could afford otherwise financially inaccessible drugs. Now, with accumulator adjustment programs being used more frequently by insurers, patients can no longer afford their treatment.

The All Copays Count Coalition, of which CSRO is an active member, is working to finalize language to be used in a bill that would allow chronic patients with serious health conditions that rely on copay assistance to continue to access their medications through the same process they currently use. The CSRO will share opportunities to engage on this issue once the bill has been filed.

## Stay in the know!

Get updates about accumulator programs, drug pricing regulations, and more directly to your inbox by joining our email list.

Sign up now at [csro.info](http://csro.info).

## ACCUMULATOR ADJUSTMENT PROGRAM



### WHAT IS THE PROGRAM?

A utilization management tool that excludes co-pay assistance as an out-of-pocket expense for the purpose of meeting a deductible

### WHY DOES THIS OCCUR?



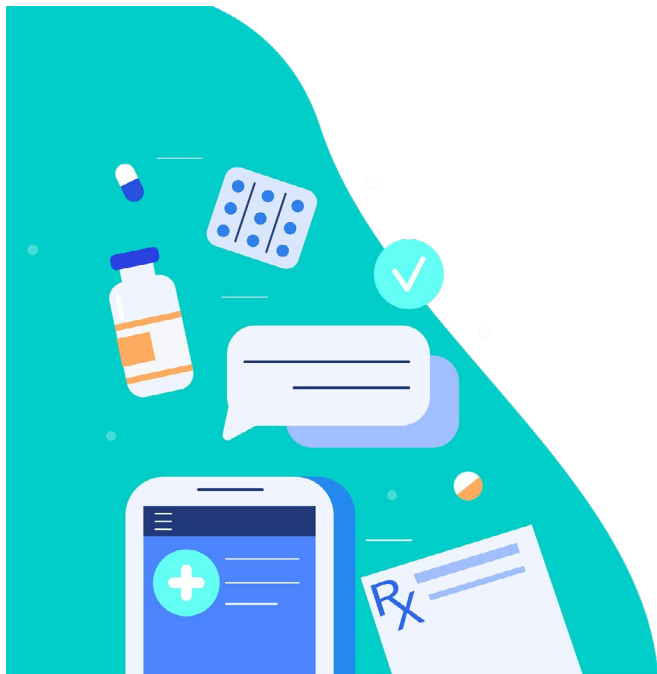
Insurers maintain that co-pay assistance circumvents payer induced financial incentives and formulary design.

### HOW ARE PATIENTS AFFECTED?



Accumulator programs are a one size fits all approach that negatively impact atypical patients with complex chronic conditions. Co-pay assistance allows these patients to adhere to medically necessary therapies. Disrupting their continuity of care causes serious adverse events and higher overall costs.

# Downcoding Policies: Medicare Administrative Contractors Continue to Push



Downcoding chemotherapy administration codes from complex to simple is not a new issue for the rheumatology community, but the way Medicare Administrative Contractors (MACs) are implementing these policies is now under new guidance from CMS.

Specifically, MACs have issued Local Coverage Articles (LCA) that direct providers to downcode the administration service(s) associated with certain medications. Some may recall that the Centers for Medicare & Medicaid Services (CMS) changed the criteria for amending administrative codes that now requires MACs to use a Local Coverage Article (LCA) instead of a Local Coverage Determination (LCD).

Unlike Local Coverage Determinations (LCDs), LCAs are not subject to notice and comment, leaving key stakeholders with limited opportunities to address problematic LCAs in advance of their effective date. MACs have been active in utilizing this new process in 2021 most of them have current policies in place: CGS, WPS, Palmetto GBA, Noridian, NGS

The CSRO has issued letters of opposition to each of these MACs to reverse their current downcoding policies and outline concerns with the LCA process. CSRO has also been in contact with CMS and hopes to develop a solution for this process that allows for our Carrier Advisory Committee (CAC) representatives to have more of an active role in the review process.





# The Effects of the Pandemic on State Legislatures: A Reflection

The onset of the COVID-19 pandemic in the United States severely disrupted state legislative sessions in the Spring of 2020. Many state legislatures shut down or significantly shortened their sessions in order to avoid large groups congregating in the tight quarters of capitols and exacerbating the pandemic. When legislatures did return to operating remotely or in person, their primary efforts were focused on state budgets and dealing with the coronavirus pandemic to the extent that they were able to. Bills that did not fall into the “must pass” category were largely casualties of this disruption. Unfortunately, many bills supported by CSRO and likeminded stakeholders fell prey to this dynamic.



CSRO Board member, Dr. Mark Box, testifies in support of Missouri HB 751 (Step Therapy)

While the 2020 legislative sessions did see some bills signed into law, the persistence of the pandemic worried many healthcare advocates that the 2021 state legislative sessions would be another year of arrested progress in the states. With travel restrictions in place and a new operating environment, advocates scrambled to adapt their tactics.

CSRO and our allies were pleasantly surprised to find that utilization management and drug pricing reform legislation was able to succeed in this new operating environment, achieving successes with step therapy bills and accumulator program bans. While there were challenges in passing non-medical switching bills, overall, as state legislative sessions for 2021 conclude, there is good momentum for change in 2022.

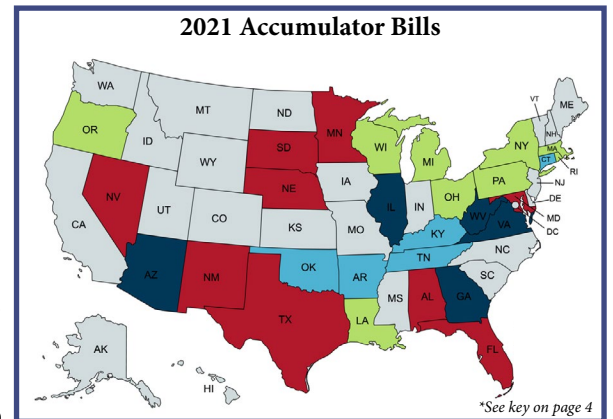
## Advancing Accumulator Bans Across the States



CSRO Board President, Dr. Madelaine Feldman testifies in support of Louisiana SB 94 (Accumulators)

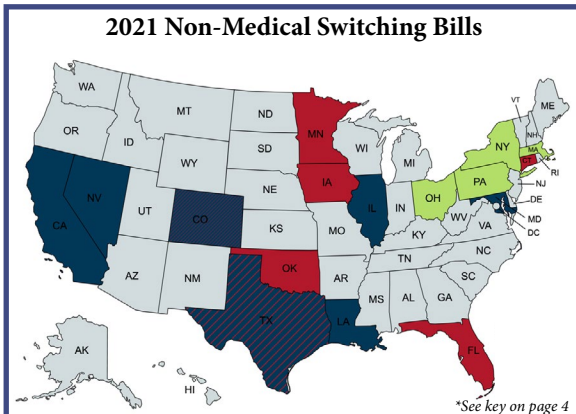
Accumulator programs emerged about five years ago as a threat to patients' ability to afford their medically necessary medications, and their use has increased significantly over the past couple of years. In realizing this trend, advocates responded by working to file legislation in a number of states to ban the use of accumulator programs in certain state regulated plans. The policy proved fairly popular, and became law in Arizona, Georgia, Illinois, Virginia, West Virginia, and Puerto Rico within two years of this strategy being pursued.

This year, over 20 more states filed legislation to combat the use of accumulator programs in their own state regulated plans, and during the 2021 session, five states succeeded to bring the total number to ten: Arkansas, Connecticut, Kentucky, Oklahoma, and Tennessee. Louisiana's legislation currently sits on the Governor's desk awaiting signature and is likely to join its predecessors as the eleventh state. While the clock has run out in a number of other states hoping to pass accumulator bills during this year's session, eight bills remain in play this year.



CSRO is encouraged by the progress made so far this year, and believes momentum will carry over into 2022, when advocates are likely to be able to travel to capitols again to emphasize the importance of these bills in person.

## A Focus for 2022: Limiting Non-Medical Switching



There has been a great degree of success in the states this year, but not all of the rheumatology community's priorities have advanced. While 11 states filed legislation seeking to limit non-medical switches, none have yet been signed into law. Legislation in Massachusetts, New York, and Pennsylvania still has chance to advance, but advocates have largely been stymied in the states this year.

Nonetheless, non-medical switching remains an important issue, and one that will occur with increasing frequency as formulary exclusions mount. To date, California, Colorado, Illinois, Louisiana, Maryland, Nevada, and Texas have some form of protections on the books - these successes give CSRO and our allies optimism for future years.

If anything, delayed progress serves as a call to action for the rheumatology community to engage more proactively in support of non-medical switching protections in the states. Stay tuned as we plan for the 2022

session for ways you can support such legislation in your state.



# Success in the States on Drug Pricing Reform



State legislatures took some encouraging steps on drug pricing with respect to patient out of pocket costs this year. A common theme of many drug pricing proposals across the country is the lack of a mechanism that ensures patients directly benefit from pricing reform. For that reason, CSRO was extremely encouraged to see West Virginia's HB 2263 signed into law, which was supported by CSRO and requires rebate savings be shared directly with patients. Specifically, the legislation reduces a patient's cost sharing at the point-of-sale by an amount equal to at least 100% of the rebate received by pharmacy benefit managers (PBMs) in connection with the utilization of the drug.

This serves to resolve the issue of patients paying coinsurance based on a percentage of the list price rather than off of the substantially discounted net-price. Indeed, the status quo seems to function something like a system of reverse insurance, where the sick subsidize costs for the healthy through their utilization of high list price, but ultimately discounted, drugs. The West Virginia bill, which was perhaps the most ambitious of these "rebate pass through" bills that appeared in the states this year, promises to directly benefit the patients most exposed to the negative externalities of the rebate system. CSRO is hopeful that other states will follow West Virginia's lead in coming sessions.

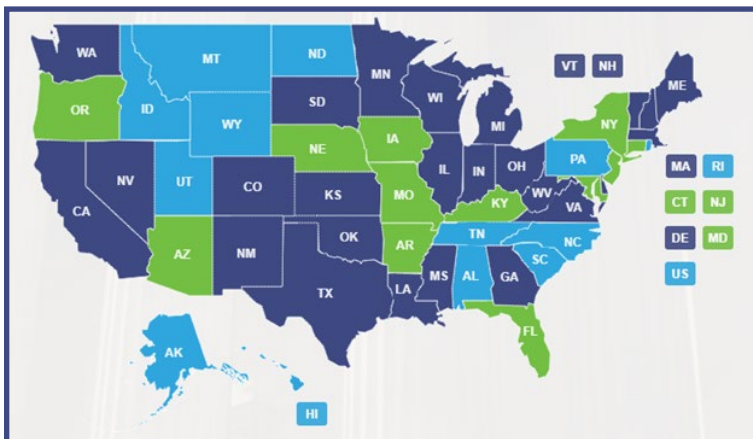
Montana also found success this year regulating PBMs and their influence on high drug prices. After then-Governor Steve Bullock vetoed a bill in 2019 to begin regulating pharmacy benefit managers, the Montana legislature revisited the issue in 2021, and Governor Greg Gianforte ultimately signed the bill into law. The legislation, like legislation that has preceded it in other states and is strongly supported by CSRO, requires PBMs to be licensed by the state and to submit a transparency report to the state every year. In addition, it also established a process to review complaints for misleading marketing and advertising by PBMs.

**New this year:** CSRO joined the GTMRx Institute as a Strategic Partner because of our common goal of ensuring the appropriate and personalized use of medications. The CSRO is dedicated to empowering rheumatologists and their practices with resources to proactively increase patient access to rheumatologic care and medication, and we look forward to how this new partnership will help us further our mission.



## Ways to Take Action

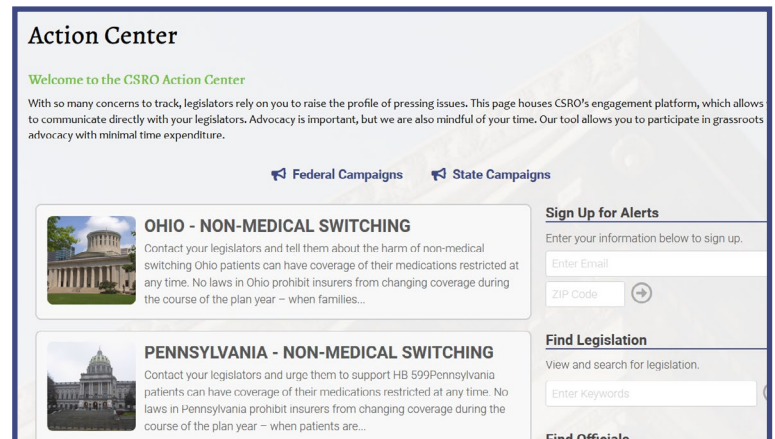
### Legislative Map Tool [csro.info/map](https://csro.info/map)



CSRO's website has an interactive legislative map tool where you can find current and proposed policy in your state!

Updated regularly, you simply visit [csro.info/map](https://csro.info/map), click on your state, and get information about legislation that can or is impacting the rheumatology community in your area.

### Action Center [csro.info/advocacy-campaigns](https://csro.info/advocacy-campaigns)



CSRO's Action Center allows you to communicate directly with your state legislators about proposed policy.

Visit [csro.info/advocacy-campaigns](https://csro.info/advocacy-campaigns) to see if your state has any pressing issues. From there, you can read more about the issue and voice your support by sending a template message to lawmakers and make an impact on your state legislation!

# Ways to Get Involved!

## JOIN A COMMITTEE

Volunteer with CSRO by joining one of our committees: Insurance, Fellows, or State Societies.

For more information on committee objectives or to express interest in joining, email [info@csro.info](mailto:info@csro.info).

## CHECK OUT OUR MAP TOOL

Find your state on our interactive legislative map tool.

Visit [csro.info/map](http://csro.info/map) and learn about current policy and ways you can take action to make an impact.

## SIGN UP TO JOIN OUR EMAIL LIST

Stay in the know by receiving our bi-weekly e-newsletter which includes current advocacy and legislation news.

Sign up now at [csro.info](http://csro.info).

## FOLLOW US ON SOCIAL MEDIA

Join the conversation on Facebook and Twitter.

Follow [@CSROAdvocacy](https://twitter.com/CSROAdvocacy) to get real time updates on rheumatology news and events.

# CSRO Supporting the Community: Advocacy and Mission Focused Grants

## SPECIAL ONE-TIME GRANT

In South Florida, the pro-bono rheumatology clinic formally known as the Arthritis Foundation Clinic provides patients who are diagnosed with a rheumatic disease and cannot afford treatment with free and consistent high-quality care, identical to what patients would receive from a private practice.

CSRO's past president Michael C. Schweitz, MD has been a volunteer rheumatologist with the clinic for the past 44 years, and when the Arthritis Foundation announced in 2020 that they were no longer able to fund this critical community resource, he brought it to the attention of the Board of Directors of CSRO.

In a year when this type of resource was perhaps needed more than ever, CSRO provided a generous grant to help replace the lost funding, allowing the clinic to stay open to its patients as it worked to find new financial backing. Now called the John Whelton Arthur Virshup CreakyJoints South Florida Arthritis Clinic, CSRO is proud of our role in maintaining its availability during the global pandemic.

## FELLOWSHIP GRANT

In recent years, CSRO has been exploring ways to more directly support rheumatology fellowships at programs in member states, and in partnership with member state societies.

We are now pleased to announce the pilot of a new fellowship grant program with an initial grant to the Children's Hospital of Los Angeles in support of their pediatric rheumatology fellowship, matched by the California Rheumatology Association. More information on the application process for the next available grant will be available to member societies in 2022.

## ADVOCACY GRANT

To better realize our mission to advocate for excellence in the field of rheumatology, ensuring access to the highest quality care for the management of rheumatologic and musculoskeletal disease, CSRO is pleased to offer an Advocacy Grant to our member societies.

This grant is intended to assist with advocacy efforts at the state level and may be used for specific advocacy activities including, but not limited to, a sponsored advocacy day at the state capitol; advocacy training for member rheumatologists; or webinar development to educate on specific issues.

Member societies interested in learning more and/or applying for this grant may visit [csro.info/advocacy-grant](http://csro.info/advocacy-grant) or email CSRO at [info@csro.info](mailto:info@csro.info).

## New Partnership with Rheumatology News



In May, Rheumatology News launched an advocacy column through a partnership with CSRO. Titled *Rheum for Action*, this column is designed to keep the rheumatology community updated on the latest advocacy issues and inspire individuals to make 'rheum' in their lives for advocacy.

The inaugural piece, by CSRO Board President Madeline Feldman, MD, shared how she got her start in advocacy work and how she continues to make time for it amongst seemingly endless competing priorities.

Watch for the column in both the online and print editions of Rheumatology News, or sign up to join our email list at [csro.info](http://csro.info) to be sure you receive the link when a new column is released!



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@CSROAdvocacy

## We Moved!

In 2020, the Coalition of State Rheumatology Organizations Board of Directors examined our needs regarding administrative management as we face the opportunities and challenges resulting from recent organizational growth while continuing to advance the mission of CSRO.

After thoughtful consideration, the Board of Directors decided to change management companies, and as of December 1, 2020, we now work with Executive Director, Inc. (EDI), located in Milwaukee, WI. Founded in 1962, they support over thirty-five national and international medical and scientific organizations, and we are confident this transition will result in the best service to you, our valued members.

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## Upcoming Events

### CCR EAST: August 12-15

CSRO will be exhibiting in Florida for the Congress of Clinical Rheumatology's (CCR) east coast meeting. If you're in town, stop by to say hello!

### STATE SOCIETY ADVOCACY CONFERENCE: September 10-11

Join us this September 10-11 for our annual State Society Advocacy Conference! This event brings together like-minded rheumatologists and advocates to network within our community, learn from nationally-recognized experts, and strategize about advocacy.

The unique program will focus on current issues at both the state and federal level impacting rheumatology patients and practices, including a panel of state legislators, insight into the impact of Rutledge vs PCMA, and more. The afternoon will feature interactive "how-to" breakout sessions on advocacy, successful payer interactions, and managing change.

Visit [csro.info/ssac](http://csro.info/ssac) for more details, including a full line-up of speakers, and free registration form - we hope to see you this fall!

### CCR WEST: September 18-21

We will also be in California for the CCR's west coast meeting - keep an eye out for the CSRO booth!

### FELLOWS CONFERENCE REVISITED: October 23

In March, we hosted our 15<sup>th</sup> Annual Fellows Conference, an event specially designed for the rheumatology community to gain insight on critical issues and skills not taught in academic training.

The conference, which was held virtually, featured key topics like personal financial management for physicians, coding updates, and the realities of private practice, all presented by field experts.

This October, we will be holding a screening of the virtual Fellows Conference, and the presenters will again join us for a live virtual Q&A immediately following the program. Save the date for October 23 and stay tuned for more information!

### SAVE THE DATE! 2022 FELLOWS CONFERENCE: March 19

We look forward to returning to San Francisco in 2022 for our 16<sup>th</sup> Annual Fellows Conference!