

President's Message



*Michael P. Stevens,
CSRO President*

As the last of the 2018 regular sessions wind down across the states, CSRO is happy to report that the year to date has been marked by a number of successes on the patient access front. As you will find in these pages, interchangeable biosimilar substitution measures continue to make rapid progress in the states, while organizations such as ours continue to make steady progress on reforming utilization management techniques. As an increasing number of states enact such reforms, CSRO will continue to work on expanding these protections to new states, but also turn an eye towards proper implementation and insurer compliance with enacted measures. These successes follow from continued engagement with policymakers by the community of patient advocates, of which CSRO plays an important role in providing physician perspectives from the rheumatology space.

In addition to directly educating legislators about the necessity of individualized care for the patients we treat, CSRO has worked to expand its coalition among the community of rheumatologists, patients, and other medical professionals. It is important that our community speaks with a consistently united and strong voice, and CSRO has attended numerous meetings and conferences this year to improve engagement within our organization and with our partners. To that end, CSRO has attended numerous meetings of the individual state rheumatology societies. By the end of this year, CSRO will have attended meetings for the following state societies: Alaska, Arizona, Arkansas, California, Florida, Georgia, Iowa, Michigan, Mississippi, Nevada, New Mexico, North Carolina, Ohio, Oregon, Pennsylvania, Texas, and Wisconsin.

Although 2018 brought breakthroughs in a number of states, they did not come without attendant challenges. Pharmacy benefit managers continue to implement new utilization management tools such as Accumulator Adjustment Programs that hamper patients' access to the medications they depend on. All too often these policies are one size fits all, circumventing the individualized care necessitated by the complexity of many of the chronic illnesses we treat.

These new challenges and intensifying opposition from health plans and PBMs only affirms the necessity of our organization's mission. It seems as though navigating an increasingly burdensome, complex, and hostile payer environment has become, as much a part of treating our patients as the medicine itself, and it is only with continued engagement that we can reverse this trend. The CSRO maintains that the best healthcare is orchestrated by the patient and their physician, and will continue to strive for reforms that fulfill this vision.

I would like to personally thank all of our members who invested their personal time in advocating for patients in 2018 and engaged with our organization. Our success would be impossible without your collective efforts and dialogue. I encourage others to join us as we carry momentum into 2019 to support policies and programs that increase patient access to care, and look forward to seeing you many of you this fall at our State Society Advocacy Conference in Chicago that serves as an important forum for these objectives. There is still time to register, and I would encourage all to attend. More information can be found on our website at www.csro.info.

Sincerely,

Michael P. Stevens, MD, FACR
CSRO President



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THE COALITION OF STATE
RHEUMATOLOGY ORGANIZATIONS

Since it was founded in 2003, CSRO's mission has been to advocate for excellence in the field of rheumatology.

CSRO Welcomes New Board Members

Before the Alliance for Specialty Medicine's annual Federal Fly-In, CSRO board members took the opportunity to discuss new and old organization business while they were gathered in Washington D.C. As part of this meeting, the board welcomed three new members that promise to bolster CSRO's ranks and reach. Each of the new members has been a champion for patients and physicians through advocacy they have performed throughout their careers, and will no doubt help CSRO fulfill its core purpose.

We are excited to introduce you to our three newest board members.

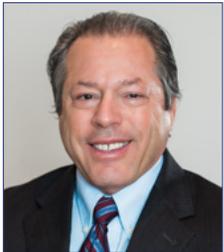


Harry Gewanter, MD, FAAP, MACR

Dr. Gewanter retired from Pediatric and Adolescent Health Partners in December of 2015 after many years of active practice of Pediatric Rheumatology. In addition to remaining active in the Rheumatology community on patient access and physician practice issues, he also serves as the Medical Director for Medical Home Plus Inc. Dr. Harry Gewanter earned his medical degree from Wayne State University. After completing his medical degree he completed his internship and residency at the University of Rochester and Strong Memorial Hospital, which was followed by a General Pediatrics Academic Fellowship in Rheumatology sponsored by the Robert Wood Johnson Foundation.

During his career Dr. Gewanter has served as a tireless advocate and pillar of the Rheumatology community in Virginia, as well as nationally. He serves as a member of the Virginia Patient Advocacy Task Force, Chair of the Virginia Arthritis Foundation Advocacy Committee, and as a board member for the Disability Law Center of Virginia. Dr. Gewanter has been particularly active in the area of biologic and biosimilar drugs, serving as the immediate past chair of the Alliance for Safe Biologic Medicines. Through his involvement in this organization he has delivered testimony on numerous occasions, including to the International Nonproprietary Naming Committee, the FDA's Oncology Drugs Advisory Committee, and the Kansas Senate Committee on Public Health and Welfare. Rounding out his advocacy experience, Dr. Gewanter has also served as Chair of RheumPAC.

Dr. Gewanter has received numerous recognitions and awards for his medical work and teaching and educational activities. He has been published in numerous times of the course of his career, with 32 professional citations to his name.



Robert Levin, MD

Dr. Levin is the Immediate Past President of the Florida Society of Rheumatology, and serves as the Chair of the Alliance for Transparent and Affordable Prescriptions. Dr. Levin earned his Medical Degree from Hahnemann University in Pennsylvania. Subsequently, Dr. Levin completed his internship and residency in Internal Medicine as well as his Rheumatology fellowship at the Medical College of Pennsylvania.

During his career, Dr. Levin has written for several publications and presented numerous lectures relating to his rheumatology specialties. Additionally, Dr. Levin has remained active in the world of academia by teaching as an Affiliate Assistant Professor at the University of South Florida. His commitment to continuing education is further displayed in his tireless research as the principal investigator in dozens of clinical trials.

Dr. Levin is board certified by both the National Board of Medical Examiners and the American Board of Internal Medicine, with a Subspecialty of Rheumatology. He is an active affiliate of Mease Hospitals, where he has worked on various quality assurance committees and served as both the Chairman of the Department of Internal Medicine and the Chairman of Rheumatology between the years 1990 and 2002. Currently, Dr. Levin is a Fellow Member in a number of medical societies, including the American College of Rheumatology and the American College of Physicians. Dr. Levin is well known in the Tampa Bay area for providing the highest standards of patient care.



Amar Majhoo, MD

Dr. Amar Majhoo, is a practicing Rheumatologist in St Clair Shores, Michigan. He is affiliated with St. John Hospital and Medical Center as well as Beaumont Hospital Gross Pointe. He is a native Michigander and earned his medical degree from Wayne State University. After completing his Internal medicine training he completed both Geriatric Medicine and Rheumatology fellowships at Wayne State University at the Detroit medical Center. He is an Assistant Clinical professor of Medicine at Wayne State University, School of Medicine as well as Oakland University/Beaumont Hospitals School of Medicine. He is involved in training of residents and fellows.

He has extensive experience in clinical trials, has been an invited guest lecturer nationally and internationally, been the recipient of numerous recognitions and awards, presented at scientific meetings and sits on both state medical and the American College of Rheumatology committees. He has dedicated countless hours advancing the Michigan Rheumatism Society and for advocacy for clinicians and patients, including testimony before Michigan House of Representatives on Biosimilars.

State Advocacy Update

Biosimilar legislation continues momentum across the states, advocates grind out victories on utilization management

2018 was an active year for biosimilars legislation as advocates have worked to pass legislation in the few remaining states that have not adopted a substitution measure. This year saw Alaska, Michigan, New Hampshire, South Dakota, Vermont, Wisconsin, West Virginia, and Wyoming, enact biosimilar substitution measures. Pending approval of these measures, 45 states and Puerto Rico will have enacted a biosimilar substitution measure. In 2019 attention will turn to the five remaining states without biosimilar substitution measures. Those states are as follows: Alabama, Arkansas, Maine, Mississippi, and Oklahoma. In addition, CSRO will work to amend existing legislation that does not provide sufficient patient protections. The prescriber notification requirement present in Texas and Virginia's biosimilar substitution laws sunset in 2019, and Florida's law does not provide for any prescriber notification.

In 2017, California, Louisiana, and Nevada had enacted some form of non-medical switching protections. CSRO staff expects Illinois to join their ranks by the end of 2018. After a lengthy battle with various PBMs and health plans, the Illinois legislature passed legislation that provides a mechanism to protect patients from non-medical switches within a plan year. The legislation awaits action by the Governor, and advocates are optimistic the Governor's office will sign the legislation into law after direct discussions with his office. Although few non-medical switching bills saw significant progress in the 2018 sessions to date, a significant number were introduced, demonstrating improved awareness of the issue area. 10 states took up such legislation this year, and they are as follows: Colorado, Connecticut, Florida, Iowa, Illinois, Maine, New York, Oregon, Pennsylvania, and Washington.

This year, New Mexico and Minnesota have enacted step-therapy protections. These two states bring the total number of states implementing step therapy protocol protections to 18. This year, Florida, Georgia, Hawaii, Kansas, Maine, Massachusetts, Minnesota, New Mexico, Ohio, Rhode Island, Virginia, and Washington have worked on legislation limiting the use of step-therapy protocols by insurers and pharmacy benefit managers. In total, 12 states worked on step-therapy legislation this year.



CSRO Vice President, Dr. Madelaine Feldman, testifies on Illinois HB4146

Legislator Education Program



Director of Government Relations, Kevin Daley, speaks to stakeholders in Connecticut

In order to improve awareness surrounding utilization management techniques and create early headway on these important issues, CSRO has organized a series of legislator education events. In working with patient and provider group aligned with CSRO on utilization management issues for these events, CSRO has also been able to strengthen its relationships with its allies.

Increasingly intense lobbying efforts by health plans and the PCMA have produced a challenging legislative environment for patient protections legislation in 2018. This has required a hands on approach to interacting with lawmakers and active legislation in the states where possible. CSRO has used the key legislator education program to improve legislator education on patient access issues in the states, and to dispel misrepresentations fostered by PCMA and health plans.

After successful events in Florida, Illinois, and New York CSRO has worked with its partners to expand the program. CSRO backed an event supporting Connecticut's non-medical switching legislation this spring. Moving forward in 2018 and into 2019, staff plans on hosting events in Florida, Massachusetts, Virginia, and Washington.

STAY CONNECTED

Stay connected with CSRO online via our website at www.CSRO.info

Accumulator Adjustment Program

Over the course of the past year, CSRO has been heavily involved in raising awareness of pharmacy benefit managers' expanding use of Accumulator Adjustment Programs. These programs detect the use of co-pay assistance, excluding such assistance from counting towards a patient's deductible or out-of-pocket maximum. These programs have serious implications for patient adherence, as when the value of their co-pay assistance runs out, they will be responsible for the full value of their remaining deductible for the year. With an increasing number of patients migrating towards high-deductible health plans, these bills can prove to be financially untenable, forcing the patients off of their preferred therapy.

As the CSRO considers policy solutions with its many partners, it has continued to raise awareness and gather information on the programs. In addition to communications sent to state insurance commissioners, CSRO Vice President, Madelaine Feldman, has presented on the impact these programs have on patients at a number of forums.

Disturbingly, however, health plans have attempted to test the waters with legislation that would stave off legal challenges raised by patient advocate organizations. Legislation introduced this in Rhode Island this year would have specifically allowed these programs under Rhode Island law. The CSRO, in coordination with its allied organizations, worked to defeat S2532 during the committee process. The legislation was successfully sidelined on the grounds that it would negatively impact health outcomes for patients with chronic illness.

The combined effort of our advocacy community was sufficient to convince lawmakers to change the proposed legislation to require co-pay assistance to count towards patients' deductibles. Although the bill did not make any progress in this form, it provides a useful template for future efforts to curb this practice.

National Conference of State Legislatures



CSRO Executive Committee Members, Doctors Greg Schimizzi and Madelaine Feldman, educate policymakers in Los Angeles.

Each year state legislators from across the country congregate to discuss innovative solutions that can be implemented to solve problems faced in common by various state legislatures. The event serves as an important educational forum for state lawmakers that can learn more about problems their constituents are facing and potential fixes.

Each year CSRO participates in this conference as an exhibitor with a number of other specialty groups as "Physicians Advocating for Patients." CSRO is afforded the opportunity to educate diverse array lawmakers about the unique concerns associated with patients suffering from chronic illnesses, and our proposals to fix associated issue. This year CSRO focused on speaking with lawmakers in states that had not yet addressed some of the various utilization management techniques implemented by Health Plans, and raising further awareness about the PBM problem.

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CSRO Responds to Drug Pricing Blueprint

In response to high prescription drug costs that continue to plague Americans the White House released its “Blueprint to Lower Drug Prices” in May of 2018. The highly anticipated document outlined numerous avenues the Federal Government could pursue to help lower prescription drug costs. Although the blueprint contained elements that would be harmful for patient access, CSRO was encouraged that the blueprint recognized problems within the system of pharmaceutical rebates perpetuated by pharmacy benefit managers.

In response to the blueprint, CSRO submitted its comments to the Department of Health and Human Services Request for Information regarding elements of the plan.

The Department of Health and Human Services has requested meetings with drug manufacturers and pharmacy benefit managers to discuss changes to the system. It is expected that the Center for Medicare and Medicaid Innovation (CMMI) will release a Rule in response to the feedback gathered from the RFI and meetings with stakeholders within the next couple of months.

In preparation, the CSRO has been gathering feedback from the rheumatology community and its patient organizations, and will seek its own meetings with CMMI.

CSRO's comments can be accessed and read in full on the [CSRO website](#).

BIO International Convention



CSRO Treasurer, Dr. Greg Schimizzi, talks patient realities.

The Biotechnology Innovation Organization (BIO) represents over 1,100 stakeholders in the biotechnology industry across the United States and internationally. BIO hosted in 2018 International Convention in Boston, and CSRO took the opportunity to attend.

In addition to advancing scientific discussions and related industry discussion around biotechnology and workforce, the event offers an unparalleled forum to educate stakeholders on issues affecting patient access, and the resulting consequences.

At the event CSRO staff was able to have numerous productive discussions with other physician and patient organizations in states that lacked safe interchangeable biosimilar substitution laws about how to advance the objective of patient safety while improving deployment of certain biosimilar products.

CSRO Treasurer, Dr. Schimizzi, and CSRO Director of Government Relations, Kevin Daley, also used the opportunity to participate in a panel discussion in partnership with the AIMED Alliance. The pair were able to talk about patient realities and the political environment for solutions on the panel, which focused on preserving the right to quality care.

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Follow the CSRO Twitter account,
[@CSROadvocacy](#) (Twitter.com/CSROAdvocacy)

Alliance for Specialty Medicine - Federal Fly In

In July, the CSRO joined numerous other specialty practice organizations and their leadership teams for the Alliance of Specialty Medicine's Annual Capitol Hill Advocacy Day. Participants were afforded an excellent opportunity to meet with legislators on issues affecting specialty practitioners at the Federal level.

Before attendees completed their visits, they heard directly from several lawmakers who have been staunch supporters of specialty practice issues. Specifically, attendees heard from Rand Paul (KY), John Delaney (MD 6th), David Perdue (GA), Bill Cassidy (LA), and Charlie Dent (PA 15th). Each delivered a forecast on the federal landscape for healthcare and provider centric legislation, and provided best practices for speaking with lawmakers.

This year the Alliance focused on the following legislative priorities:

1. Maintaining a Viable Fee for Service Option in the Merit-based Incentive (MIPS) Program
2. Resident Physician Shortage Reduction Act (HR 2267/ S 1301)
3. Prior Authorization and Step Therapy
4. USPSTF Transparency and Accountability
5. Local Coverage Determination Clarification Act (HR 3635/ S 794)
6. Medical Liability Reform



Clinical Congress of Rheumatology



*CSRO Vice President,
Madelaine Feldman with
AWIR Vice President,
Dr. Gwenesta Melton*

The annual Clinical Congress of Rheumatology Conference draws over 500 physicians from across the United States, and CSRO continued its commitment to participating in 2018. CSRO board members and staff traveled to participate in sessions and exhibit to attendees. CSRO used the opportunity to engage attendees and vendors, educating them on issues such as pharmacy benefit managers.

With the Clinical Congress of Rheumatology also representing the largest gathering of rheumatologists aside from the annual American College of Rheumatology Conference, it was an excellent opportunity to network with colleagues who can become more heavily involved in advocating for patients. CSRO provided advocacy tips, and information on how to get involved with CSRO and the state rheumatology societies.

As ATAP Celebrates One Year Anniversary, Successes are Undeniable

A year since the Alliance for Transparent and Affordable Prescriptions (ATAP) officially launched, considerable progress has been made in the states and at the federal level. The coalition is now twenty members strong.

Federal Highlights

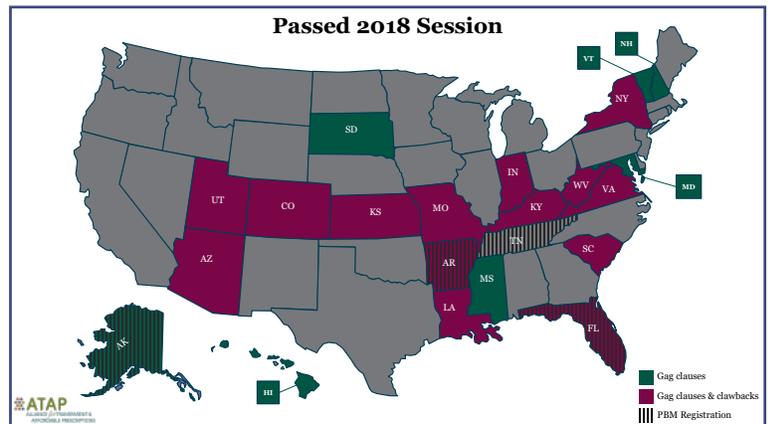
Most recently, ATAP's focus at the federal level has been on the Trump Administration's blueprint and request for information, entitled American Patients First, on lowering drug prices and reducing out-of-pocket costs. ATAP submitted comments supporting the administration's desire to address the pharmaceutical rebate system. ATAP also issued a statement applauding the White House recognizing the increasingly harmful role of pharmacy benefit managers (PBMs) in the prescription drug market in a report outlining policy options to reduce drug prices and encourage medical innovation. Importantly, the report included specific ATAP policy recommendations, including enhancing competition in the PBM market and mandatory pass-through of discounts to patients.

Earlier this year, ATAP issued a statement applauding UnitedHealthcare for its new policy to pass on savings from drug manufacturers directly to patients by applying manufacturer rebates and discounts to their medication costs at the point of sale, and FDA Commissioner Scott Gottlieb, MD for his statement emphasizing the importance of biosimilar competition in bringing down the rising prices of biologics.

State Highlights

ATAP is pleased to report that over eighteen states have now passed legislation this year aimed at regulating PBMs in yet another sign that our coalition's core message and extensive advocacy outreach is continuing to resonate not only with state lawmakers, but also with the general public. See the list below for a comprehensive overview.

Now that session is officially winding down, ATAP will focus on evaluating and analyzing how best to proceed in terms of introducing our state model bill in certain target states. We will also be considering how to use transparency provisions that were recently enacted (i.e. Louisiana SB 283, Connecticut HB 5384) to gain information on PBM practices and further our policy goals.



CSRO OFFERS NEW GRANT PROGRAM

Earlier this year, the CSRO launched an initiative to formalize its membership process. Our hope is that this effort will strengthen the relationship between CSRO and its members and also prompt state organizations to participate more actively within CSRO. The CSRO is made up of state and regional rheumatology societies and our mission is to support you in turn.

We would like to thank the 27 states societies who have formalized their relationship with us thus far. We are pleased to offer these member societies a wealth of resources to help support their individual society mission and goals. The CSRO monitors state and federal legislation, works with state societies to submit comments and provide testimony on key issues, and provides its members informational materials for both patients and legislators. Beginning immediately, the CSRO will also offer grants to member societies to help fund their own advocacy initiatives.

The CSRO has set aside funding for member societies to assist with advocacy efforts at the state level. Funds may be used for specific advocacy activities including, but not limited to:

- Sponsored advocacy day at the state capitol
- Advocacy training for member rheumatologists
- Conference registration fees
- Specific issue webinar development

To be considered for a CSRO Advocacy Grant, member societies must complete an application and submit to the CSRO Executive Office. Member societies may submit an application to fund any activities that support advocacy for issues that affect rheumatologist members.

Make sure to attend the CSRO Annual Business Meeting at the 2018 State Society Advocacy Conference to learn more about the grant process and the criteria for receiving a grant. Applications and more information can also be found on the CSRO website.

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REGISTER TODAY!

STATE SOCIETY ADVOCACY CONFERENCE SEPTEMBER 14 - 15, 2018

Register online for CSRO's State Society Advocacy Conference, September 14 - 15, 2018, at the Westin O'Hare in Rosemont, Illinois. The conference provides rheumatologists and other practitioners the opportunity to learn from experts about advocacy best practices and get in-depth with the issues that affect you and your patients. **You can register online at csro.info/ssacreg. Online registration closes 9/4/18!**