



[Patient Voice - Spring 2023 Issue](#)

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2023 Health Care Policy Trends and Priorities

Nearly three years after its onset, the COVID-19 pandemic continues to effect providers, insurers, patients providers, nonprofits and other stakeholders in the healthcare industry. The US healthcare industry faces demanding conditions in 2023, including recessionary pressure, continuing high inflation rates, labor shortages, and the lingering effects of COVID-19. Trends this year include rising hospital expenses as staffing shortages and a reliance on contract labor continue to plague systems, even as facilities face ongoing burnout and a surge in worker strikes. Coupled with inflation, rising expenses this year could lead to clashes at the bargaining table between payers and providers as clinicians attempt to negotiate higher payment rates. Meanwhile, payers are looking ahead to a looming potential recession and are scrutinizing commercial medical and pharmaceutical utilization amid widespread national layoffs.

With all the uncertainty and higher costs for patients one thing that is evident to the NAF is that strong, cohesive and organized patient advocacy for the protection of accessible health care in general is essential in today's cost driven environment. Without such advocacy, the debate will be focused on measures that are designed to provide short term savings, at the expense of patient health and long term costs. Patient based advocacy on areas related to general health care and access to medications/treatments is critically needed. Just a few of the many priority policy areas the NAF follows and will advocate for in 2023 include:

- **Promote Telehealth Options** - While telehealth use has fallen from record highs at the beginning of the pandemic, patients are still turning to virtual care, with volumes expected to shift from urgent visits to chronic care management. Providers will also start to weave artificial intelligence into their workflows, including in areas like revenue cycle management, clinical decision support and patient engagement. Healthcare providers will also face pressure this year to invest in and adopt better technology to combat cyberattacks, which have risen in volume and severity over the past few years. The NAF will continue to promote telehealth options for patient access to care and extend/make permanent COVID telehealth flexibilities.
- **Inflation Reduction Act (IRA) Implementation** - Shape implementation of IRA and ensure that regulators at CMS create specific opportunities for patient advocates to participate in the regulatory process.
- **340B Must Benefit Most Vulnerable Patients** - Build momentum for proactive federal legislation on 340B reform and ensure that the neediest patients receive the Program's benefits and that profits do not go to chain pharmacies or out of state pharmacies.
- **Patient Affordability & Access** - Drive pro-patient policies that make costs more predictable and affordable for patients (utilization management, prior authorization, step therapy)
- **Support Rare Disease Advisory Council (RDAC) Creation/Implementation** - An

RDAC is an advisory body that gives the rare community a stronger voice in state government. RDACs address the needs of rare disease patients and families by giving stakeholders an opportunity to raise awareness and make formal recommendations to state leaders on the most important issues they face. With over 7,000 known unique rare diseases, it is difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness contributes to the obstacles that rare disease patients and their loved ones face. RDACs can use their diverse membership and broad community support to identify barriers and propose solutions to help the rare disease community.

- **Support State Newborn Screening (NBS) Bills** - Every year, states introduce new legislation affecting newborn screening programs. These pieces of legislation vary and do things like change the fee for newborn screening, add disorders to the state screening panel, and amend the timeframe in which newborn screening must take place. The NAF also supports legislation that requires the state to mirror the federal Recommended Uniform Screening Panel (RUSP) for their universal NBS programs.
- **Copay Accumulator Bans** - Copay accumulator programs allow health insurers and Pharmacy Benefit Managers (PBMs) to prevent copay assistance given to patients from counting towards their deductible and maximum out-of-pocket spending. This practice reduces the cost to payers while placing an extreme financial burden on patients, who then are forced to pay out of pocket to reach their full deductibles or forego their life-saving medications because they can't afford it. Sixteen states and Puerto Rico have already banned the use of copay accumulators. Many more bills have been introduced in 2023 in an attempt to help patients.
- **Pharmacy Benefit Manager (PBM) Reform and Regulation** – PBMs are companies that manage prescription drug benefits on behalf of health insurers, large employers, Medicare Part D drug plans and other payors. By negotiating with drug manufacturers and pharmacies to control drug spending, PBMs have a significant behind the scenes impact in determining total drug costs, shaping patients access to medications and determine costs to patients and pharmacies. A majority of states have passed bi-partisan legislation regulating PBMs but more is needed to increase transparency, improve accountability and advance rebate pass through/share the savings with patients.

New Book Release: “Sleep to Heal: Refresh, Restore and Revitalize Your Life”

A new patient resource book authored by Abhinav Singh, MD, MPH, FAASM with Charlotte Jensen was recently published by Humanix Books. The new and unraveling science of sleep reveals that sleep impacts everything from anxiety and creativity to productivity and longevity. It's an essential pillar of health – perhaps even more important than nutrition and exercise. No matter what a person's goals are – better sleep, losing weight or simply feeling more patient around loved ones – it is never too late for a sleep reboot. Based on scientific research and 15 years of clinical experience

of a double board-certified sleep physician who has taught the art of sleep to more than 15,000 patients, [Sleep to Heal](#) will reshape the way readers think about sleep and give them the strategies and tools needed to transform life from the inside out – one peaceful night at a time.

Thank You for an Unforgettable and Impactful #RareDiseaseDay

On Tuesday, February 28, 2023, the National Organization for Rare Disorders (NORD) and the global rare disease community celebrated Rare Disease Day. We came together to:

- Join in events held across the country both in person and virtually, which included several of ORD's Centers of Excellence, Rare Action Network (RAN) chapters, Students for Rare, and more.
- Celebrate thousands of individuals who joined our **#ShowYourStripes** campaign by posting photos in their zebra gear.
- Dedicate 600+ personal stories and sentiments on NORD's **Rare Disease Day Dedication Wall**.
- Illuminate hundreds of buildings and landmarks in Rare Disease Day colors as part of the global **#LightUpForRare** campaign.

Later this month, after additional Rare Disease Day events conclude, we will share a full recap. Rare Disease Day events are continuing into the month of March, be sure to check out upcoming events [here](#).



A New Resource!

A new book, **“Explaining Neuropathy: Symptoms, Diagnosis and Treatment”** has been recently published and is an updated 2022 edition that was previously published as the American Academy of Neurology Quality of Life Guide. The book is written by, Dr. Norman Latov, for people with peripheral neuropathy and for those that care for them.

Preserving Patient Access to Home Infusion Act

A diverse group of 30 patient and stakeholder groups, including the NAF, are calling on Congress to address Medicare beneficiary access to home infusion services. In a **letter to lawmakers**, which brings together stakeholders from across the care continuum, the groups urge congressional leaders to advance the *Preserving Patient Access to Home Infusion Act* (**S. 2652/H.R. 5067**) and increase access to home infusion therapy for Medicare beneficiaries.

“Home infusion therapy services have been a lifeline for millions of Americans by delivering lifesaving treatments to patients while reducing costs, infection risks, and unnecessary facility visits,”

the groups write. “Unfortunately, despite Congress’s efforts to establish a dedicated Medicare home infusion therapy (HIT) benefit, the Centers for Medicare and Medicaid Services (CMS) has implemented it in such a restrictive manner that is it failing to promote patient access.”

The letter goes on to cite a **report released by the Centers for Medicare and Medicaid Services (CMS)** in January 2022 confirming that utilization of the benefit has been low. “Recent data released by CMS suggests that less than 1,300 Medicare beneficiaries accessed the home infusion benefit each calendar quarter between Q1 2019 and Q1 2021, a massive outlier compared to the estimated 3.2 million patients served annually by home infusion providers,” the letter states.

Background on the ‘Preserving Patient Access to Home Infusion Act’

Congress included provisions in the *21st Century Cures Act and the Bipartisan Budget Act of 2018* to create a professional services benefit for Medicare Part B home infusion drugs. The intent in establishing this benefit was to facilitate patient access to home infusion by covering professional services including assessments, education on administration and access device care, monitoring and remote monitoring, coordination with the patient, caregivers and other health care providers, and nursing visits.

Despite Congress’ intent — **as detailed in multiple letters to the agency** — the Centers for Medicare and Medicaid Services (CMS) improperly implemented the benefit by requiring a nurse to be physically present in the patient’s home in order for providers to be reimbursed. As a practical matter, the current home infusion therapy benefit only acknowledges face-to-face visits from a nurse, failing to account for the extensive clinical and administrative services that are provided remotely by home infusion clinicians. As a result, provider participation in Medicare’s home infusion benefit has been limited and beneficiaries have experienced challenges in accessing home infusion over the last several years.

The *Preserving Patient Access to Home Infusion Act* provides technical clarifications that will remove the physical presence requirement, ensuring payment regardless of whether a health care professional is present in the patient’s home. The legislation also acknowledges the full scope of professional services provided in home infusion — including essential pharmacist services — into the reimbursement structure. If implemented, this legislation would increase provider participation in the benefit and enhance patient access to home infusion, effectively diverting care to the home that would otherwise be delivered in more expensive institutional settings.

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