

Patients First!

By Tyler Wilson

The editorial focus for this issue of *INFUSION*, “Putting Patients First,” speaks to our nation’s ongoing efforts to put the patient at the center of health care while improving outcomes and cutting costs. The issue encourages new ways to connect with patients amidst the swirl of the evolving health care landscape and shares best practices and different perspectives on home and specialty infusion care, including a look at how patient experience programs can improve both quality of care and patient satisfaction.

As health care professionals, we owe it to our patients to explore these big-picture topics—to examine the most recent research on caring for central vascular access devices, understand how patient satisfaction measures will shape future reimbursement models, and consider how our face-to-face interactions affect patient care. At the same time, we owe it to our patients to advocate on their behalf, never forgetting that they are a single policy decision away from losing access to vital home and specialty infusion services.

That is where we find ourselves today. The *21st Century Cures Act*, while having the potential to positively impact the lives of millions of patients, contains a provision that threatens Medicare beneficiary access to vital home infusion services, particularly for the most vulnerable of patients—those on inotropic therapy for heart failure and subcutaneous immunoglobulin therapy for primary immunodeficiency diseases (see Ken Van Pool’s “Advocacy in Action” column on page 14 for more details). For more than a decade, NHIA has warned of the dangers of average sales price (ASP)-based reimbursement for home infusion drugs without a payment for the pharmacy services required to deliver therapy to patients. Now we are facing just such a scenario—reimbursement levels that, for many providers and therapies, are less than the cost of providing care.

Creating a sustainable environment for providers and ensuring patient access to safe, effective infusion care at home, is a top priority for the home infusion community and the Association. NHIA has embarked on a multi-level strategy to push Congress to move quickly on this issue. The strategy includes Congressional lobbying, advocacy with the Trump Administration, press outreach, tracking patient hardship data, and coalition building. Recently, more than 170 home infusion providers and partners, patient advocacy groups, hospital systems, physician groups, medical societies, and associations signed onto a letter urging Congress to act early in 2017 to close the four-year gap between the January 1, 2017, implementation of ASP and the 2021 scheduled implementation of the infusion services payment specified in *Cures*. We recognize the immediate, deleterious effect this gap has on beneficiary access to care, and we must work with our coalition partners to raise awareness with those in policymaking circles.

It’s imperative that we understand and document what happens to patients when they go off service—or are no longer referred to home infusion providers. Where do they receive care? Does the new site of care present challenges, or risks they would not experience at home? Quantifying these variables is problematic, but necessary. And, no one can make the case better than patients themselves.

I encourage each of you to take a few critical steps toward helping us pull together vital information that can illustrate our point from the perspective of those the Medicare program is designed to serve. Patient stories, or testimonials, are one of the most effective means of communicating with lawmakers. If you know of a patient who is directly impacted by the ASP reimbursement issue and is willing to share his or her experience, we would like to capture their narrative. A microsite, “Keep My Infusion Care at Home” has been established to raise general awareness about the impact of ASP reimbursement on patients and to serve as a vehicle for collecting stories. You can access the site at: www.keepmyinfusioncareathome.org. Talking to patients about the site and the importance of telling their story is a simple, but vital way to support this important effort.

The unintended consequences for home infusion patients of the *Cures Act* underscores the complexity of health care delivery in our country. It is our responsibility to speak up when the focus on patients is inadvertently shifted or distorted in the pursuit of budget and policy goals.



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