

## The Time for Action is Now

by **Russ Bodoff**

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In my various columns over the years I have discussed the need for compelling patient stories to help us bring to life and clearly illustrate the real challenges faced by older and disabled Medicare beneficiaries, who are unable to receive home infusion therapy due to the lack of a comprehensive Medicare benefit. With your support, in 2009 we did receive a dozen excellent stories from our member companies for use in conjunction with our major, immensely successful Congressional event that NHIA hosted on the Hill. Beyond being leveraged to help secure the highest number of Senate and House co-sponsors that any home infusion legislation has ever reached to date, those captivating patient stories also led to a variety of press coverage—including significant media features in *The Wall Street Journal* and on NPR (National Public Radio). Unfortunately, since 2009, that critical flow of patient stories has totally dried up.



To help demonstrate just how much of an impediment the lack of such “real life stories” generates in our advocacy work, let me share a “snap shot” of the type of challenge that John Magnuson (NHIA’s Vice President of Legislative Affairs) and I face up on the Hill, when meeting with members of Congress and their staffs:

**Member of Congress:** “Your cause really sounds interesting. We do need to find health care savings and I greatly care about my constituents. Do you have data that shows what the cost savings of a home infusion benefit would be for the Medicare program?”

**NHIA Staff:** “It is difficult to presently collect or show that type of data, since Medicare does not offer meaningful home infusion therapy coverage for its beneficiaries.”

**Member of Congress:** “I can see how that can be a Catch 22. Can you share with me some of your latest examples of patients actually suffering because of the lack of a meaningful benefit?”

**NHIA Staff:** “We really don’t have current examples to share with you.”

**Member of Congress:** “Well, I will think about your legislation. Please let me know if you get any current information that shows how this really impacts my constituents.”

The above exchange would actually be quite comical, if it was not so horribly true. Of course the dialogue we engage in on the Hill usually includes additional savvy statements, where we try to passionately and methodically “make our case” with the limited data and resources we have on hand. But in the end, the above example accurately conveys the ultimate bottom line outcome that often results. We are fighting a battle on behalf of our members, and the patients they care for—but we are frequently doing so without the proper “ammunition” that is so urgently needed. And that is repeatedly a showstopper.

While it is understandably difficult to produce the Medicare savings data commonly asked for, patient stories are attainable. Since my arrival here at NHIA in February 2007, I have visited many NHIA member companies. And every time I talk to their intake staff I hear a constant message about “no goes,”—the Medicare patients that cannot be treated due to the lack of a meaningful benefit. Without question, we need to bring those “no goes” to life. We need members of Congress, the Secretary of Health and Human Services (HHS), the Acting Director of the Centers for Medicare & Medicare Services (CMS), and the media to all vividly see, feel and understand what the lack of a home infusion Medicare benefit does to these patients. If we allow the hardships faced by such Medicare patients (and their families) to remain an unspoken secret, there is no pressure on those in Washington to make the much-needed change. We need those patient stories—which is to say, we need your help to identify and send us those stories.

I may sound like a broken record—but I cannot emphasize enough how important these patient stories are to John and me in successfully delivering our crucial message. Such real life stories are also critical to any home infusion stakeholder seeking to engage in productive grassroots efforts. When facing the difficult limitations of data challenges, there is no better way of compelling members of Congress to act than to bring the adversities of their own constituents to life—especially in an election year.

Please contact John at [John.Magnuson@NHIA.org](mailto:John.Magnuson@NHIA.org) or 703-838-2664 if you can help. Thank you.

*Russ*