Abbie 

If you are a patient who has been told future treatments with your brand of IVIG will not be possible, here are some steps you can take:

1) If being treated in the home, ask if there is another brand to which you can switch. If no product is available, talk to your ordering physician about another homecare provider.

2) If being treated in a physician’s office, ask if there is another brand to which you can switch. If no product is available, look for other sites of care. Specifically, check with the hospital where your ordering physician has privileges. Or, check with a homecare provider.

3) If being treated in a hospital outpatient infusion center, go back to your ordering physician and ask about another outpatient center. Or, check with a homecare provider.

4) Consider exploring the subcutaneous route of infusion if it makes sense for your condition.

**Question | What can be done to reduce the side effects of IVIG to treat myasthenia gravis (MG)?**

*I have MG, and for the last decade, I've been treated with intravenous immune globulin (IVIG) infusions every three to four weeks, after which I experience severe headaches and nausea about 48 hours after the infusions. My new neurologist prescribed acetazolamide (Diamox) starting four days prior and three days after infusions, as well as Depakote (divalproex sodium) for seven days starting the day of infusion. Although my last infusion resulted in a 20 percent decrease in headaches and nausea with this protocol, the headaches still required injections of 30 ml of ketorolac, 50 mg/ml of promethazine (Phenergan) and long-acting lidocaine scalp/eyebrow injections. Additionally, the infusions have been slowed during the last three months to 90, and my neurologist has added Benadryl, Decadron and Zofran prior to starting the infusions. My next infusion is in 11 days, and while the intense headache has subsided, I am still experiencing malaise and brain fog, which makes it very challenging for me to work. These symptoms are also taking a significant toll on the MG; my symptoms are worse than they've been in more than five years.

My neurologist says I am experiencing aseptic meningitis, and she is taking steps to change my brand of IVIG. Do you have any other suggestions? Are there other drugs that could be used to treat the symptoms?*

Abbie

I spoke with Leslie Vaughan, senior vice president of clinical programs at Nufactor, a specialty infusion company, regarding your question. To reduce your symptoms, she suggests asking your physician to switch brands of your IVIG or slow the rate of your infusion even further. According to Vaughan, some patients can’t tolerate even a rate of 90. She also recommended infusing a large dose over several days or infusing on nonconsecutive days. Lastly, she suggests you ask your physician if he or she would consider you a candidate for Soliris, which is approved for MG and has a much lower side effect profile than IVIG.

**Have a question?** Email us at editor@IGLiving.com.
Your information will remain confidential unless permission is given.

**ABBIE CORNETT** is the patient advocate for IG Living magazine.