

ASK KRIS



IG Living is pleased to introduce Kris McFalls, the newest addition to our IG Living team. Kris will function in a role that's a bit of a spin on the traditional ombudsperson: Instead of responding to complaints (thankfully, we don't receive many!), she will respond to questions from our readers. And these we do receive—about all kinds of things!

Kris has two adult sons with chronic diseases treated with IG, and she is currently on the challenging quest for her own diagnosis. Formerly a physical therapist assistant, Kris is an avid patient advocate and now works with NuFACTOR, a sponsor of IG Living. Kris is eager to find answers to your questions. Email them to editor@igliving.com.

Barbara: Are there other diagnoses that go hand-in-hand with primary immune deficiency diseases (PIDD)?

Kris: I was at a conference where this very question was addressed. The doctors at the conference reported that indeed there are certain diseases associated with PIDD. However, the causes of the links are unknown. The doctors said the following diseases are more frequent and commonly seen in people with PIDD, especially common variable immune deficiency, and in family members of PIDD patients:

- hypothyroidism or Hashimoto's disease
- inflammatory bowel disease
- ulcerative colitis
- certain types of lymphoma
- arthritis
- other autoimmune diseases

Now, keep in mind that while they are more common in certain PIDDs, the doctors at the conference said there is currently no way to predict which patients will contract them.

Lisa: I currently use intravenous immune globulin (IVIG) for myasthenia gravis. I was wondering if subcutaneous IG (SCIG) would be an option for me.

Kris: There is no clinical data on the use of SCIG for autoimmune or neurological diseases. However, if you are serious about trying SCIG, gather as much information as you can, and share it with your doctor. Send him or her the information before your appointment, so you are both prepared to discuss it. Listen to what your doctor has to say, and make sure you are making decisions based on all the information. But don't be afraid to push a little to make your points.

Betty: Thank you for your recent article that mentioned intravenous immune globulin (IVIG) infusion rates. My only problem with the article is I could not translate the rate equation, as it is not in plain English. Is there a way to say what my rate should be in lay terms?

Kris: IVIG infusion rates can be very confusing, I agree! The rate referenced in the article is only one manufacturer's guidelines. Actual infusion rates vary—by product and by individual. Your rate should depend on your weight and on how you feel and what your reactions are to infusions.

All manufacturers recommend infusion rates in their product package inserts as guides, and these guides can certainly be used to start new patients. However, IVIG is often administered in a "ramping" fashion, meaning the rate of infusion starts out slowly and then is increased in increments until a maximum rate is obtained. This allows the patient to slowly become accustomed to the infusion. Each patient's infusion rate must be individualized to each brand of IVIG. Bottom line: Ask your doctor to explain your rate to you, and talk about any uncomfortable reactions you have to your infusions. ■

Have questions about living comfortably with your IG therapy?
Send them to Ask Kris at editor@igliving.com.