

The



of Tracking Healthcare Treatment

The best way to ensure that IG treatments are working is to maintain good health records. Here's why and how.

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Gone are the days of patients placing blind faith in doctors and the healthcare system. In this age of ever-expanding and complex diseases, as well as the plethora of information available online to all, individuals can and should now take a proactive approach to their healthcare. This approach extends from keeping up to date on disease state issues, to playing a role in diagnoses and, even more important, maintaining health records. And, while keeping good records of healthcare treatment applies to all patients, it is of paramount importance to individuals who rely on immune globulin (IG). As IG patients well know, information pertaining to their health, including symptoms, side effects, medications, allergies, lab results, surgical procedures and more, is the only way to ensure that their IG treatment therapy is working. Following are the ABCs of tracking treatment.



Accounting for One's Own Health

When physicians and infusion nurses are asked whether IG patients should keep track of their treatments, their answers will vary. According to Heather Lawson, RN, an independent infusion nurse, it's common when patients have their infusions in the hospital or in an infusion clinic for doctors not to recommend patients track their treatments. This is because the facility is required to keep the information so that the doctors can easily access it if necessary. And, she says, even if patients have their infusions at home, the home healthcare company keeps the information on file via the nurse's paperwork. "However," she explains, "the patient should keep their own book, because it is easy to obtain the information ... regardless of location ... and then the patient has a record and continuity of care."

In fact, it also is the experience of Dr. Carol Koski, MD, retired professor of neurology at the Maryland University School of Medicine and medical board member of GBS-CIDP Foundation International, that “most doctors do not recommend patients keep their own records of intravenous immune globulin (IVIG) use.” But he, along with other physicians, agrees with Lawson that patients should. Records “can be very helpful, particularly when moving, seeing a new physician and for [making] the patient aware of which products, rates, etc., they tolerate best,” says Koski. In addition, for physicians to monitor safety and tolerance of a product, as well as that product’s effectiveness in preventing infections and other complications, record keeping by patients “is imperative,” says Dr. Ricardo Sorenson, MD, chairman of the Department of Pediatrics at Children’s Hospital, New Orleans, La. “If you don’t know which product was used and how it was given, it hinders taking corrective measures.” For instance, says Koski, if an adverse reaction occurs, a patient being seen for the first time may mention an allergic reaction to IVIG, but may not be able to remember the type of reaction, the timing or the brand they were on.

Even for the doctors who regularly see the same IG patients, personal records “can be very helpful during clinic visits for identifying problem areas and making any necessary changes in the treatment plan,” says Dr. Marc Riedl, MD, MS, section head of clinical immunology and allergy at the University of California, Los Angeles, David Geffen School of Medicine. But, that doesn’t mean it happens. “I haven’t had much success in actually getting patients to track or provide this specific information,” adds Riedl, and “because so few actually do this, I’ve come to rely on the home healthcare companies or infusion centers to provide the data on infusions, reported side effects and history of infections/antibiotics” — information that can be helpful in making dose adjustments, changing products or lots in the event of side effects, and tracking the efficacy of the treatment over time.

In case patients underestimate the importance of tracking their treatments, Lawson says she’s seen all kinds of mistakes occur with poor records or in situations where records don’t exist. “I have had the wrong medication shipped to the home. I have had the wrong dose sent. I have had patients have some very severe reactions to the medications,” she says. “I have had patients who receive one brand of IVIG at home only to be given a different brand of medication when the patient was in the hospital. [And,] I have patients who don’t tolerate infusions in

certain locations on their arms or [who have] certain veins that don’t work well. This is why continuity of care is so important, and being your own advocate is essential.”



Best Accounting Practices

The best accounting practices are detailed. Records should include not only treatment details and notes, but also other healthcare information. While this may seem a little tedious, once information has been initially recorded, it can become routine to regularly add information to keep it current.

Basically, this will be a “health diary.” It will include all essential information, as well as diet and exercise regimens, symptoms, infusion timelines, side effects, medications, allergies, surgeries/procedures, lab results, insurance information, etc. Here’s what to include:

Personal information. Start by logging all personal information, such as height, weight in pounds and kilograms (divide pounds by 2.2 for kilograms), address, home and cell phones, occupation and travel history.

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Symptoms. Any PIDD-related symptoms, such as infections, response or lack of response to antibiotics, joint pain, change in bowel habits and increased fatigue, should be logged, including the type of symptom, when it occurred, how long it lasted and what was done, if anything.

Medication. List the names of all medications with the dose and frequency (prescribed doses for medications can



be found at www.accessdata.fda.gov/Scripts/cder/DrugsatFDA), and how the medications are taken (i.e., subcutaneously, intravenously, orally). Note why the medication is being taken, and list whether the dosage differs from what is normally prescribed. The brand name as well as the generic name should be included, if applicable. Also, make a note about whether the medications cause interactions when taken with other medications. And, don't forget supplements; they are drugs, too.

Allergies. If allergies to medicines exist, the type of reaction (e.g., rash, breathing difficulties) should be recorded, as well as how quickly the allergy developed after taking the medication. List the name of the medication causing the allergy and any similar medicines that may cause the same kind of reaction. (For instance, if a patient is allergic to Ceclor, are they allergic to all cephalosporins?) Also list whether the reaction resolves on its own or whether medical intervention is required and what type. Is the reaction serious enough to require the patient to carry an EpiPen? If so, note whether any type of medical alert identification is worn.

Surgeries/procedures. If hospitalizations have occurred, list when and why. List the types of surgeries and procedures that have been undergone, as well as the dates they occurred. In addition, all immunization dates should

be logged, and if unable to receive immunizations, indicate which ones and why.

Lab results. Lab results should be kept side by side to show trends (this is especially important because what is considered the normal range may not be normal for the patient). Also list the names of the doctors and their contact information (including office and fax numbers and email addresses), and their lab diagnoses.

IG treatment. Last, but certainly not least, is a thorough list of all IG infusion treatments. This is important so that doctors can better assess whether treatment is working and whether the dosage is correct. In addition, these records will help justify continued therapy and help to decrease the expense of repeat and unnecessary testing.

What should be tracked during treatment? The date of the treatment; the product, lot number and dose (usually in grams); rate of infusion (usually in milligrams per hour) and infusion time; infusion site (rotating the placement of the IV keeps veins as healthy as possible); side effects and/or reactions; interval history with intercurrent infections; other medications given; and days of school/work missed.

Insurance. Insurance information should include the name of the company, the identification and group numbers, and the name of the case manager (if there is one), as well as their contact information. If possible, keep a copy of the insurance card with the records.



Choosing a Tracking Method

There is no reason to start from scratch when creating health records. Many existing logs, both in paper and electronic form, are available. Here is just a sampling of what patients can choose from (many other record keeping products also are available):

- NuFACTOR Health Diary. Patients can track symptoms side by side with their infusions so their doctors can quickly see the response to treatment and make any needed adjustments. This diary is great for people who like to be short and sweet, and it charts an entire month on one sheet, making it simple to spot trends in symptoms and how they relate to infusions. NuFACTOR also offers a paper infusion log and an emergency medical card containing information needed in an emergency on www.nufactor.com or by calling (800) 323-6823.
- IG manufacturers' infusion logs. Most manufacturers

of IG provide some form of infusion logs to patients. For instance, Baxter offers patients a complimentary Wellness Kit 2010, which includes both the Wellness Tracker and Wellness Organizer. The kit was designed by primary immunodeficiency patients and caregivers to help patients get organized, track infusions and communicate with their treatment team. It can be obtained at www.immunedisease.com/patients-and-families/help-and-support/baxter-resources/wellness-kit.html. Patients should check with their product's manufacturer to see what kind of logs they provide.

- **HealthHuman.** This in-depth online solution (available at www.healthhuman.com) allows patients to track and analyze all areas of health, from medical history and records to diet, exercise, lifestyle and more. Membership to the site is free, although upgrades are offered for more extensive record keeping.

Patients Setting an Example

With the right tools, patients can easily maintain their own health records, and we found that many do. *IG Living* conducted a poll on its Facebook page (which can be accessed at www.IGLiving.com) to assess whether, where, when and how patients keep their records. While responses varied, here's a sampling of what we heard from the respondents who do keep records:

"I keep a binder with all of my son's blood-work results, vitals, discussions with the doctor on treatment days, as well as the identification information on all bottles of IVIG," says Nicole Bird Kofoed. "When we go to the pediatrician or other specialists, everything they ask questions about is right there in my binder. It is not only helpful, but comforting as a parent to know that all that information is at my fingertips if it is ever needed."

"I have a list of all my medications, doses, etc., in my computer, [have] shrunk it down to business card size, laminated it and keep it in my wallet with doctors' names and phone numbers," explains Lisa Wooding. "I have labs every week [and] one of my doctors suggested I make a spreadsheet so when I see my immune deficiency doctor, who I only see twice a year, or get sent to a new doctor, they can look at [it] ... instead of flipping through the multiple pages of labs. [I] have also kept track of all my surgeries, dates, doctors, locations, any complications, etc.... When I have to see [a] new doctor or need another surgery, I just take a printout so I don't have to rewrite it in the three blanks they provide. Same with my medication list.... [And,] when I go to the doctor, I will take copies of the latest labs in case they

have not received [them]. It's not a wasted appointment that way."

"When I was on IVIG, the hospital and, then, my at-home nurse kept my infusion logs. Now that I am on subcutaneous IG, I keep it (Vivaglobin supplies one, and you can also get one on the Immune Deficiency Foundation site, if I remember correctly)," says Sheri Hewson Rader. "There, I track the globulin batch numbers, days I received the infusion, what I took before and during, and how I felt afterward. Oh, and where I had the infusion, which helped me find the best spots to have them with the least topical problems! I also write about any colds, infections, fevers or any problems I've been having, and there's a spot for questions for the doctor. I never go to an appointment without the log. And, I now save them to see how I have progressed. I highly recommend taking the few minutes to do this!"

Tracking IG treatments is important so that doctors can better assess whether treatment is working and whether the dosage is correct.

As our poll samples demonstrate, everyone has their own tracking style. Some patients will choose to track a lot of details, while others will choose to log just a few items. The key is for patients to pick their own comfortable level of detail and to be consistent about tracking it.

As Easy as ABC

The bottom line is that patients are their "own best medical professional," says Lawson. "Ask questions, talk to your doctors and infusion nurses, take notes and keep a record of all your care. Be an active part of your own care." It's as easy as ABC: accountability, best practices and choosing the right tools. ■

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