



July 2015

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Infusion Options

Choosing an Infusion Environment

Patients need to consider a number of factors, including cost, convenience and safety, when determining which environment is best for

them.

By Heather Claverie
(Reprinted with permission from IG Living)

Laura Rohe knows a thing or two about infusion options. At age 14, the Omaha, Neb., resident was diagnosed with common variable immunodeficiency.

Thank you to all who joined us in Los Angeles on June 18 at the Intercontinental Hotel Century City for our 9th Annual "Neuropathy Action Awareness Day." A very special thank you to our sponsors and exhibitors who made this event possible. This year over 700 patients, caregivers and others attended the event either in person or through the latest live streaming technology. A few highlights include:



Dr. Melina Jampolis talked about how nutrition helps prevent disease.



Dr. Richard Lewis gave a neurologist's approach to diagnosing neuropathy.



NAF Founder & President **Dominick Spatafora** shared his journey with MMN.



Special thanks to Jessie Pavelka for his inspiring and motivating words!



9th Annual Neuropathy Action Awareness Day a huge success!



The NAF had a **record high 18 Exhibitors** this year!

During this information-packed day, patients, caregivers and professionals in the field were

She counts herself as one of the lucky few to receive such a quick diagnosis since, on average, a patient will spend 12 years waiting for one.¹ Now 40, Rohe has spent the vast majority of her life receiving intravenous immune globulin (IVIG) infusions to maintain adequate antibodies to prevent infections. For 22 of those years, she first received IVIG in a hospital, then at home and then in a doctor's office. Four years ago, she switched over to subcutaneous IG (SCIG) therapy, and she infuses in the comfort of her own home. "I feel like my health is better because I'm getting the steady infusion every week, with the convenience of doing it at home and less side effects," says Rohe, who is also a registered nurse for Allergy, Asthma and Immunology Associates in Omaha.

Types of Infusion Environments

Home, hospital, outpatient infusion clinic or doctor's office? Those are the choices facing patients who are treated with IG. Until the 1980s, patients were required to remain in a hospital setting for infusions. But when expenses became a major factor for insurance companies, they began looking for alternatives to the costlier hospital infusions.² That's the main reason for such significant growth in home-based

infusions, says Leslie Vaughan, senior vice president of clinical programs for NuFACTOR Specialty Pharmacy.

Individuals may receive infusions in their homes, an option that, unlike clinical settings, offers convenience, privacy and flexibility. For example, home infusions eliminate the need to drive long distances for treatment for those living in remote locations. In addition, they allow patients to schedule their infusions at their convenience.

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During this information packed day, patients, caregivers and professionals in the field were provided with multiple educational sessions and a sit-down luncheon. The NAF looks forward to hosting another successful event next year! If you missed the event this year or just want a recap of the information you learned [click here](#).

Patient Resource

How to Sccessfully File for Disability

The odds of being approved the first time when filing for disability will vastly improve if you plan ahead and follow some simple steps.

By Cynthia Perry
(Reprinted with permission from IG Living)

THERE USUALLY ISN'T a single day or symptom that leads a patient with a chronic illness and his or her medical team to decide when work is no longer an option. Instead, you may suffer a gradual decline in your ability to juggle all of life's demands: family, work and social obligations. At some point, your boss may ask why you have so many doctor appointments, or why you miss so much work. Co-workers may wonder why you are sick so often. Over time, you may find that almost every hour you aren't at work you spend asleep: work, sleep, repeat. These are all good indicators that filing for disability may be necessary.

Planning for Disability

Follow these steps to plan for disability:

Review private disability coverage. It's a good idea to hire an employment lawyer to review your company's disability policy; a reputable lawyer will normally do this for a few hundred dollars, and this is money well spent. A lawyer will be able to tell you about any pre-existing condition clauses, how much coverage you have, cost of living accelerators (rare in private insurance), if and how your benefits would be taxed, whether you have to apply for Social Security disability (SSDI), and what if any monies will be deducted from your long-term disability payments. He or she can also explain under what circumstances your coverage will end (usually your last day of employment), and what happens if you are fired, laid off or quit. Perhaps most importantly, a lawyer can explain any clauses about "own profession" vs. "any profession" in your policy, and give you some guidance relating to your particular medical condition; however, keep in mind that a lawyer is not a medical professional.

Review SSDI requirements and benefits. Social Security's website has a wealth of information about eligibility for disability benefits and the application process. There are two ways to speed up the Social Security application process. The first is "compassionate allowance" for people with amyotrophic lateral sclerosis and certain types of cancer; you have to be terminal to qualify this way. The second is to qualify under "List A." This is a list of conditions so severe that Social Security grants "automatic" disability (assuming you meet the specific criteria under the listings). Study the List A criteria closely, and see if you meet any of them.

You can also find out from Social Security what your benefits would be, and if and how they would be taxed. You can do this online or in person at your Social Security office. Ask doctors for support. As you meet with your various doctors for other issues, talk to them about what is going on at work. Ask them very directly if they would support your filing for disability. Talk to them about anything that you have that meets the SSDI List A criteria. Ask them if they would complete disability paperwork. If you do file for disability, list only the doctors who said they would support your disability claim. You are in control of which doctors your private insurance and SSDI contact.

Document everything at work. Document everything that happens at work, just in case you ever need that information. Keep this in your briefcase or purse in case you are ever escorted out of the building with no warning. Also, keep all of your private disability benefits paperwork in your briefcase, car or home for the same reason. Track symptoms. Track every one of your symptoms every day in a spreadsheet. You will find it enlightening, and perhaps frightening, to see how much your chronic illness is impacting your life. When you file for disability, you will need to provide this information to both private insurance and SSDI.

Filing for Disability

Once you and your doctors decide it is time to file for disability, stop work (either as forced by your employer or as recommended by an employment lawyer); you can't be working when you file for disability. Make filing for disability your new full-time job.

[Click here to continue reading](#)

Planning for Disability

- Review private disability coverage.
- Review SSDI requirements and benefits.
- Ask doctors for support.
- Document everything at work.
- Track symptoms.

Filing for Disability

- Get copies of medical records.
- Contact patient advocacy groups.
- File for SSDI and private insurance.
- Summarize symptoms with a symptom tracker.
- Summarize doctor appointments.
- Provide a prescriptions summary.
- Submit peer-reviewed medical journal articles.
- Explain chronic illness's impact.
- Request applications be reviewed by a board-certified specialist.

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