



# Sites of Care: What's Best for You?

## An Infusion Center With a Heart at Its Core

By Jeff Siegel

*This is the first in a series of articles on sites of care for patients receiving immune globulin therapy. We will explore care in the home, a hospital outpatient clinic and an infusion center. The decision on the best site of care for the individual patient can be affected by multiple factors, including disease state and severity of the disease, the method of IG administration, reimbursement issues, and patient and physician preference. The best way for a patient to be involved in the decision-making process is to understand his or her options, so here we go!*

Lori White, dressed in nurse's scrubs, stands over the shaker machine, a bottle in her hand. Eight of the 10 spots on the machine have bottles in them, and she adds the ninth. The bottles, filled with specific IVIG mixtures, are shaking back and forth, the liquid inside moving in small circles, up and down the sides of the bottle. She checks the dial on the machine and sees the speed is set at 2.

"How long do they need to mix?" she says, repeating the question put to her, but focused on the job at hand. "It depends, but about 15 minutes."

Meanwhile, a couple of her colleagues are checking the dental office-sized chairs—six in one room, 15 in the second, larger room—that will soon be filled with patients. Another colleague is looking through a sheaf of papers. It is only 8:30 in the morning, and the patients won't arrive for another 30 minutes or so, but the nurses who run the infusion center at the Texas Neurology Center in Dallas have already been at work for a couple of hours. For them, though, it is not just a job.

Talk to the men and women who work at the center—and their patients—and it's something else, something

much more important. Each of them uses words like “family” when they talk about what goes on at the center, and that what goes on is about a lot more than practicing medicine.

“I don’t think it’s being immodest to say that we genuinely care about the patients, that we care deeply about each and every one of them,” says White, RN, CRNI, who runs the infusion center. “And I think the patients realize that, and it adds another level of excellence to what we do.”

### A Day in the Life

The Texas Neurology Center takes up three floors of a bank building in Dallas’ Lakewood neighborhood. It has been treating patients since 1993, and its 12 physicians specialize in a variety of neurological areas, from amyotrophic lateral sclerosis (ALS) to multiple sclerosis (MS) to sleep disorders. The infusion center treats about 110 patients a month, mostly adults, who suffer from diseases such as myasthenia gravis, an immune disorder that shows up as muscle weakness; polymyositis, muscle inflammation caused by white blood cells that invade the muscles; and chronic inflammatory demyelinating polyneuropathy, or CIDP, which starts with a numbness in the toes and can lead to muscle weakness in legs and hands.

While the center may sound to some like just another doctor’s office, to the people who come here, it is far more than that.

“I’m just thankful there’s a place like this that I can come to,” says Robert Connell, 78, a retired airplane industry executive who lives in suburban Arlington and drives almost an hour in rush hour traffic to get infusions for his polymyositis. Connell spends three to four hours once a month in the infusion chair, and has been doing so for about two years. “Thanks to these people,” he says, “I can play golf, work in the yard, drive my car. I have no limitations except for my age.”

That’s what the staff loves to hear. They are an experienced group that remembers wearing traditional nurse’s caps. Greg Wood, RN, is the rookie, with 18 years of nursing experience. Even more important, they are something White says is a rarity: “Good infusion nurses are few and far between.”

White started out as an intensive care nurse several decades ago, and moved to infusions at Baylor Medical Center in Dallas (where she still works a couple of days a week). She has, for the most part, seen IVIG from its beginnings to today, and notes that perhaps the biggest change is where infusions are done. Today, it’s an outpatient procedure done in clinics such as hers, hospital outpatient

clinics or in the home, as opposed to the old days of hospital stays and hospital pharmacists.

Karen Courtney, RN, CRNI, has been a nurse for 28 years, working in oncology before White recruited her to work at Texas Neurology in 2001. The biggest difference she has seen, she says, is that infusion is not nearly as threatening to the patients as it has been in the past. “They have more confidence in the procedure,” she says, “and they know we’re going to look after them.”

Margaret Hastings, RN, who took her nurse’s training in Great Britain, worked as a nurse in the United States and then left the profession about 10 years ago to do marketing for several health-related businesses. Three years ago, she received a call from White, who asked her to come to work at the center. “Our goal is to create the least institutional environment we can,” she says.

Like White, Wood also came to Texas Neurology from Baylor, where he worked in a variety of home healthcare units, which included doing infusions. Wood took his training in Arkansas, after a very short career working in a soft drink bottling plant. A friend told him nursing would be a better job, and Wood had his doubts, but, “it turns out that this job showed me I had strengths I never knew I had,” he says.

### Making Small Talk

On this day, Connell is sitting next to Anthony Grizzaffi, 65, a retired banker, who drives in from a country town called Terrell, about 30 miles east of Dallas. He suffers from CIDP, which means a 4 1/2- to 5 1/2-hour infusion once a month. The two men are waiting for a couple of White’s colleagues, who are wheeling IV stands toward the pair. Their talk turns to Dallas’ pro basketball team, which is in the middle of the playoffs, a vacation trip to Louisiana and Mississippi, and even British politics.

That’s when Hastings, a Briton who has lived in the U.S. for 40 years, comes over and joins the conversation. Later, she says, “The two best things about this job are the patients and that I get to work with my best friends,” motioning to the three other nurses in the room.

There’s that family closeness again. J. Theodore Phillips, MD, PhD, a board-certified neurologist who runs the ➤



center's MS practice, notes that it's not unusual to see patients come from hundreds of miles away, as far as west Texas, New Mexico, Oklahoma and Arkansas.

"I think they enjoy the sense of community," he says, sitting in his research-cluttered office. "It's a time for them to visit, not just with people they like but with people who have similar problems. Of course, they're not alone in this. That's what the doctors and nurses are doing, too."

Another distinction: There appears to be very little of the discord that sometimes goes on between doctors and nurses in other healthcare facilities. Here, each group treats the other with genuine respect and acknowledges that they get along much better than at other practices. "We're extremely pleased with our staff," says Dr. Phillips, "and I think that shows in what happens here."

In fact, sit and listen while patients are undergoing their infusions, and a couple of things become clear. First, there is acceptance of their conditions, and a willingness to do what's necessary to fight it. Scott Wilson, 35, a truck mechanic from north suburban Lewisville, has been having infusions for eight years, once a month for six hours, for his myasthenia gravis. His family makes adjustments; his employer makes adjustments, and has been willing to give Wilson the time off for his IVIG. "This can be very tough," Wilson says, "but it's now more of a pain than anything else. And it's a lot better than

plasmapheresis [his previous treatment]."

Second, it's not easy. Not everyone wants to chat about the process, and some prefer to sit in a corner, away from the others, and read or sleep. Mae Chan, 82, of Dallas, has CIDP, which causes numbness in her legs, and she receives a three-hour infusion every month. "Yes, it was a big adjustment," she says, noting that getting to the center is difficult, since she doesn't drive. "Would I rather be

doing something else? Of course. But if I have to have it done, this is the place I would like to come to. It always looks very nice."

### Helping Themselves

Perhaps the most intriguing thing about the infusion center is that most of the patients are well-versed in both their diseases and their infusions. Says White: "Obviously, the technology has changed and improved our ability to help nurse patients. But what has also changed is that the patients are very much educated. Technology has empowered more of them to take control of their health."

Technology, in this case, is the Internet. Connell can talk about his many tests – he discussed his various CPK results (a blood test that measures creatine phosphokinase levels, a chemical or enzyme in muscles) and his treatments like a physician. Connell credits his knowledge to his research on the Internet, something he felt he needed to do, so he would know what was going on during his visits to doctors and hospitals.

Less helpful, it seems, are the insurance companies that reimburse for immune globulin treatment. Grizzaffi, who credits infusion for restoring his life to most of what it was before he was diagnosed, has had a lengthy correspondence over the past several years with both his carriers and the state agency that regulates health insurers. The catch, he says, is that as soon as the treatment works and he can walk, his insurance won't cover additional treatments—until, that is, he gets bad enough again so that he can't walk.

"That's the frustrating part of the job," says White. "You can see the patients deteriorate in front of your eyes when their insurance changes. I just wish they wouldn't be so difficult in approving [IVIG] use for the patients."

Patient decline is something no one wants to see.

"If it wasn't for this, I'd be in a wheelchair," says Grizzaffi. "I was ready to try anything. So I came in here, and now I'm walking. That's a miracle."

It's also part of why the staff enjoys their jobs and their patients so much. Says Courtney: "It is a team effort, and it is like a family. We know what's going on in their lives, and they know what's going on in ours. It's part of their routine now, and it's part of ours. And we can see the improvement in chronically ill people, which is the most rewarding part of the job. That's what makes us so passionate about our jobs."

Because, in the end, that's what the center is all about. ■



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