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IMMUNE GLOBULIN COMMUNITY

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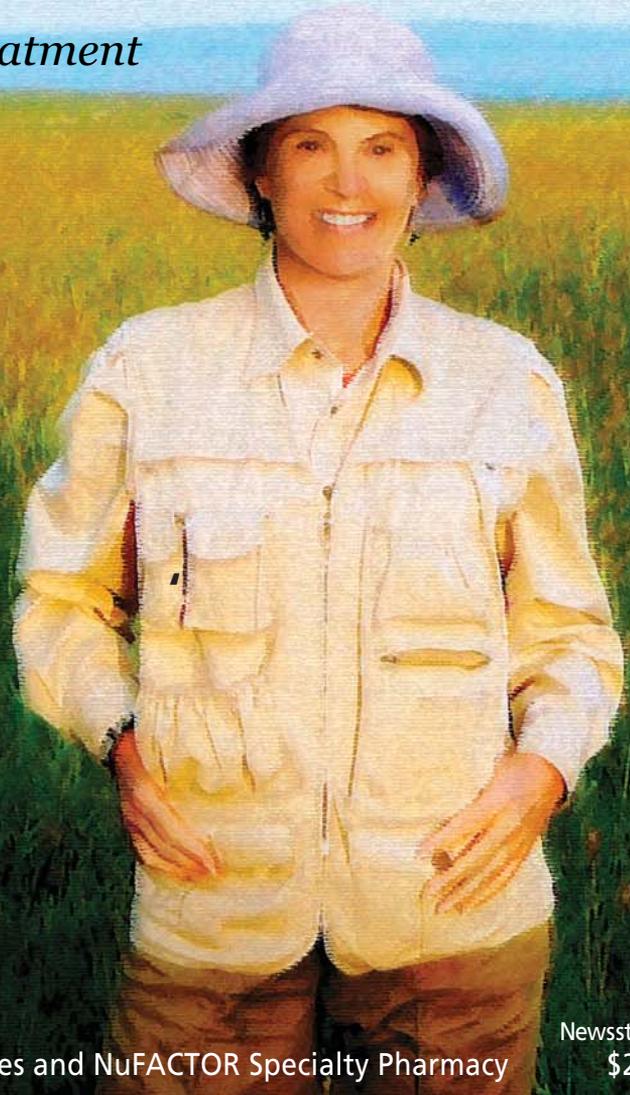
From America to Africa

Traveling With IG Treatment

Expanded Feature

Ask Kris:
Answers to Your
IG Questions

Learn About
**Multifocal Motor
Neuropathy**



A community service from FFF Enterprises and NuFACTOR Specialty Pharmacy

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About IG Living

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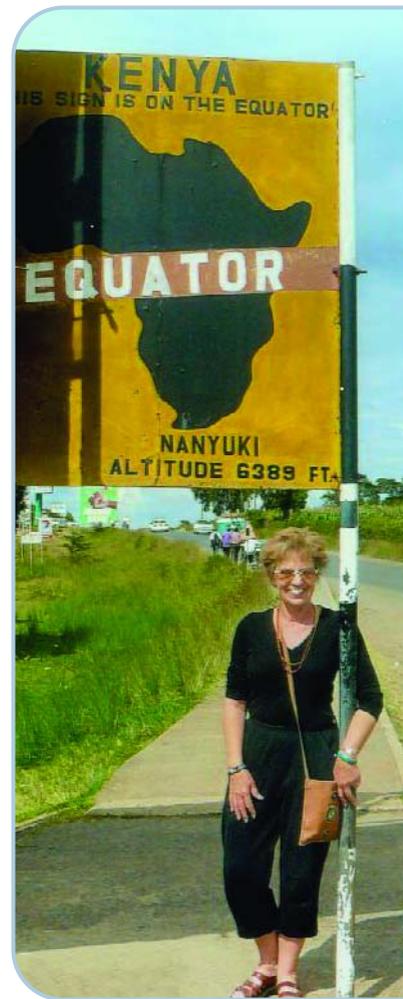
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Cover:
Nancy Hoffman, framed by Masai Mara, a game reserve in Kenya, is featured in From America to Africa: Traveling With IG Treatment.



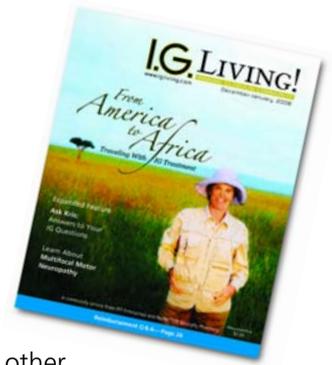
Join an IGL Readers Group!

We hear from many, many patient and family member readers who would like to connect with others in their geographic areas—to share their experiences living with chronic diseases or maybe just to have a cup of coffee with folks who understand.

We can help you determine if there's a patient organization support group in your area or help you start an IG Living Readers Group.

To join a group or start one in your own area, visit www.igliving.com and click on IGL Readers Groups.

A Little Leave and Take



What do you do in a crisis?

One parent I know, with three chronically ill children, jokes about diving into adult beverages. I'm quite certain she doesn't, but the humor of her frequent proposal is itself some welcome relief, I think, and the image of crawling through one's favorite tippie has some entertainment value.

Physical exertion is a great escape from problematic angst. There's nothing like free-flowing endorphins to temper a good crisis—and there's certain wisdom in taking a poke at a ball rather than a head.

Talking is good, although talking to oneself is generally considered unseemly, which makes talking with people who can relate to what you're talking about a superior choice.

Finding perspective is also good. You know, sandwiching the crisis between the things in your life that are good, pleasing, satisfying; that can shed new light on a crisis, a light that reveals what's truly important and what you can let go.

Based in Southern California, many of the folks who help create *IG Living* were affected by the October wildfires. Some sat home, anxiously waiting it out. Some were ordered to flee. And others watched from the sidelines as horrific video images seemed to show the end of the world. They all had one thing in common though. They all pondered what to pack, what was most important to them, what they would take if they had to escape with the contents of one vehicle.

A pillow, food and water, medicines, birth certificates, passports, tax records, marriage licenses—and divorce decrees—were popular selections. Pets and photos were the evacuees' essential accoutrements of the season. Kids might take a favorite toy—no matter if it were broken—a football uniform, a well-worn hoody, the always attached iPod.

Other than some basics, we mostly found ourselves choosing the sentimental over the dollar value, the sepia-toned memory over the new acquisition. We were pretty darn quick to categorize what could be replaced and what was poignantly irreplaceable. Of course, our CFO took his art collection and left his tax records hopefully behind. But mostly, we made swift, almost unthinking choices, amid the chaos and fear.*

And when we settled into our temporary sanctuaries and surveyed what we brought, we laughed and cried,

we were relieved and disappointed, and we looked at each other and were grateful for the camaraderie—that thing that came with us without having to be packed. And our absent friends and loved ones were also with us—via phones and email—concerned and caring. They too reminded us of what was really important.

You see, not everyone had time to pack much, if anything. And some lost it all, every tangible thing. But my friends who walked through the remaining rubble and ash, still they turned and held onto each other.

And my 80-year-old neighbor who wanted to share her adult diapers with another evacuee who'd forgotten clean underwear, she really knew what was important.

And another neighbor who defied the evac order and stayed behind, armed against the enemy invasion that never came, explained with a broken voice that, yeah, it was just a house, but it was the home in which his wife survived her cancer, in which his son grew into a man.

And another neighbor who asked her husband to bring the artichoke dip, knew well its comforting capabilities, although, in his distraction, her husband grabbed a package of emery boards instead.

So, crises are no fun. Loss is no fun. But the people we love, the neighbors we care about, they are really fun. And the next time the dog licks the numbing cream off your kid's SubQ site or you're spewing an amazing green, maybe you can pull out the sandwich makings, remember what you have and what you love, remember what's really important to you, and just get through it.

If all else fails, I have an 80-year-old neighbor who'll share her Depends with you. ■

Kit-Bacon Gressitt, Editor

* We strongly recommend making a family emergency plan—before you experience an emergency. There's a good outline at www.sdcounty.ca.gov/oes/docs/FamilyDisasterPlanPersonalSurvivalGuide.doc.

Please send your letters to the editor to editor@igliving.com.

Nutrition News Bites for 2007

By Jessica Schulman, PhD, MPH, RD

Every year, the news is filled with reports of research on nutrition and health, a flurry of facts and statistics that can be dizzying. 2007 was no exception. With all of the conflicting claims and complex information, it can be difficult to identify the new findings with the greatest potential to improve quality of life. This article provides a synopsis of a handful of notable research findings from the past year that may be especially relevant for the *IG Living* community. While the findings may be applicable to many of our readers, it is important to always consult with an experienced physician before starting any new medical therapy—medication, supplements, diet or otherwise.

Shedding Light on Dark Chocolate

Few people have to find more reasons to eat chocolate; eating chocolate is its own reward. Yet it is comforting to know that, in addition to being delicious, chocolate may confer health benefits, at least when consumed in moderation. In fact, chocolate, derived from a bean on the cacao (kah-KOW) tree, has been used for medical purposes for thousands of years by people all over the world. Dark chocolate contains polyphenols, substances that have been found in other foods such as tea, walnuts, fruits and vegetables, which are associated with positive health outcomes. A recent study published in the *Journal of the American Medical Association* suggests that chocolate intake has specific implications for cardiovascular health.



How Was the Study Done?

Researchers conducted a randomized, investigator-blind controlled study to see if small amounts of chocolate consumed regularly over a period of 18 weeks would reduce blood pressure. Participants were randomly assigned to one of two treatment groups: one that received polyphenol-rich dark chocolate containing 3.1 grams of cacao (about the size of two small squares of a candy bar) and one that received polyphenol-free white chocolate.

Who Were the Lucky Participants?

Forty-four male and female volunteers, ages 55 to 75, participated in the study. All were in good health (e.g., normal plasma lipids and glucose levels), except for mild or stage 1 hypertension. Participants were not eligible if they had illnesses such as diabetes, hyperlipidemia, gastrointestinal

tract disease, hepatic and renal disorders, among others. Blood pressure and plasma were monitored.

What Were the Results?

Small amounts of dark chocolate reduced blood pressure and improved production of bioactive nitric oxide. It is notable that, after six weeks of consuming chocolate, there was no statistically significant reduction in blood pressure. After 12 weeks, however, blood pressure had declined for those who continued to eat small amounts of dark chocolate but not for those volunteers who ate white chocolate.

Does It Matter?

By the end of the study, there was an overall reduction in blood pressure: On average, systolic blood pressure was -2.9 (1.6) mm Hg and diastolic blood pressure was -1.9 (1.0) mm Hg. This was enough to change classification for a few participants from “hypertension” to a “pre-hypertensive” state. The scientists concluded that, for those who are otherwise in good health, a couple of small squares of dark chocolate consumed daily have the potential to lower blood pressure over time. For now, this must be considered a tentative conclusion, because the participants were not blind to their condition in the study (i.e., those receiving the white chocolate probably knew they were not receiving the polyphenol-rich chocolate). ➤

Original Reference: Effects of Low Habitual Cocoa Intake on Blood Pressure and Bioactive Nitric Oxide, Dirk Taubert, MD, PhD; Renate Roesen, PhD; Clara Lehmann, MD; Norma Jung, MD; Edgar Schömig, MD, *Journal of the American Medical Association*. 2007;298:49-60.

Vitamin D: Are You Deficient?

Vitamin D is known to be essential for strong bones, but its role in health is actually much broader. Vitamin D impacts genes, including those responsible for immune modulation, C-reactive protein, cellular proliferation, differentiation, apoptosis, angiogenesis of normal cells and cancer cells. Yet despite the crucial role of vitamin D in health, most people do not get enough of it. In a recent article, Dr. Michael Holick of the Boston University Medical Center, Department of Medicine, reviewed the existing literature on vitamin D to assess the scope of the problem and determine optimal levels of vitamin D to prevent chronic disease in specific populations.

Scope of the Problem

Dr. Holick suggests that undiagnosed vitamin D deficiency is very common even if awareness of this problem is low. His review indicates that nearly one billion people worldwide have suboptimal vitamin D levels. Many groups are affected, including elderly men and women, postmenopausal women, adolescents, children and physicians. Dr. Holick reports that greater than 40 percent—and as high as 100 percent—of community-dwelling older adults (i.e., not at institutions) in the United States and Europe are deficient in vitamin D.

Does Vitamin D Help More Than Bones?

Among children, vitamin D deficiency is known to result in softening of bones (rickets), but it may show up as osteoporosis and muscle weakness in people of all ages. Scientists are now starting to understand how vitamin D also affects a host of other diseases such as autoimmune conditions, infections, certain cancers, and cardiovascular and muscular diseases. For example, Dr. Holick points out that people who grow up closer to the equator (and thus get more exposure to the sun, an important source of vitamin D) have a much lower risk of developing multiple sclerosis. Similar observations have been made for women who consumed > 400 IU of vitamin D per day. Additionally, there are reports that describe how vitamin D reduces complications from arthritic conditions.

What Do the Studies Show?

Clinical trials that had individuals consume about 400 IU of vitamin D3 per day did not show impressive results for reducing fractures. However, scientists have reported that higher doses of vitamin D (700–800 IU) do reduce risk of fractures once optimal blood levels of the active form of vitamin D3 (1,25-dihydroxycholecalciferol) were achieved. In addition, muscular fitness such as strength, performance and speed increase when patients are repleted with vitamin D.

What's the Latest Recommendation?

Most experts agree that children and adults who do not get appropriate sun exposure may need as much as 800 to 1000 IU of vitamin D per day through their diets. This is higher than previous recommendations. One serving of oily fish will provide about half of the recommended amount and one tablespoon of cod liver oil provides the whole dose (1360 IU). In general, about 800 IU of vitamin D3 per day for children and adults is adequate for health. In addition, sensible sun exposure on the arms and legs (5 to 30 minutes depending on the time of day, pigmentation, latitude, etc.) twice a week is suggested. In about 10 minutes, a fair skinned individual produces > 10,000 IU of vitamin D. Patients using certain medications or living with certain disorders, such as chronic granulomatous disease, are more sensitive to serum vitamin D levels. Although it is difficult to achieve vitamin D toxicity, it is always advisable to consult with a physician before using supplements.

Original Reference: Vitamin D Deficiency, Michael Holick, PhD, MD, *New England Journal of Medicine*. 2007;357(3);266-281.

Hard Truths About Soft Drinks

Sugar-sweetened sodas are more popular now than they have ever been. In 1970, for example, per capita intake of non-diet soda was 22 gallons. In 2000, per capita consumption had increased to more than 50 gallons. Because the prevalence of obesity has risen similarly over the same period, especially among children, researchers and policy-makers have begun to pay attention to the implications of sugar-sweetened sodas for health and disease. In some major U.S. cities, public schools have set limits on soft drink sales to their students.



Are Schools Overreacting?

Most studies describing associations between soda intake and disorders, such as obesity and diabetes, have been inadequate. Recently, however, researchers at Yale University conducted a meta-analysis that evaluated 88 major studies that assessed calorie intake, weight, milk intake and calcium among those who consume soda. Aggregating across all of these studies, consumption of soda was strongly associated with decreased nutrition status and increased risk of medical problems.

How Did They Support Their Findings?

The authors evaluated one study that followed about 90,000 women for eight years. Those who consumed at least one serving of soda per day were two times as likely to develop type 2 diabetes. In addition, 10 of 12 cross-sectional studies showed that soda consumption was associated with excess calorie intake. Apparently, individuals failed to compensate for that extra soda at school or that jumbo soda at the movies. In fact, the researchers suggest that this “liquid candy” may calibrate people’s tastes to a high level of sweetness—making them more likely to choose other “empty calorie” or highly sweetened, nutrient-poor foods. This may explain why 13 studies showed that soft drink consumption was related to a lower intake of nutrient-rich foods (such as dairy products, fresh fruit, dietary fiber, calcium-rich foods, riboflavin and others).

What’s the Bottom Line?

When the soda studies were categorized by those funded by other sources and those funded by the food industry, the industry-funded studies showed less negative outcomes than the unfunded studies. Regardless, there was a strong association between sugar-sweetened soda consumption and higher calorie intake across all studies. Researchers recommend that the public decrease soft drink intake because it contributes to obesity and several key health problems.

Original Reference: Effects of Soft Drink Consumption on Nutrition and Health: A Systematic Review and Meta-Analysis, Lenny R. Vartanian, PhD; Marlene B. Schwartz, PhD; Kelly D. Brownell, American Journal of Public Health. 2007;97(4):667-675.

Analgesic Effects of Omega-3s

For years, omega-3s have been used as a complementary therapy to treat joint pain and rheumatoid arthritis. Today, marine fish oil, a rich source of omega-3 polyunsaturated fatty acids (PUFAs), is gaining the attention and respect of patients and professionals because it has been associated with anti-inflammatory effects. Through complex mechanisms, components of omega-3 (EPA and DHA) moderate activation of factors, such as cytokines and prostaglandins, that affect inflammation. But how much should a patient use? How long should it be used?

This article is intended for general informational purposes only. Individuals with chronic conditions should consult their physicians to determine what eating pattern is appropriate for them. The author is a credentialed dietitian, holds a doctorate in health behavior, and is a visiting scholar in the Department of Psychology at the University of California, Los Angeles.

What Was Done in This Study?

To better understand the pain-relieving effects of omega-3s in patients with rheumatoid arthritis or joint pain, researchers conducted a meta-analysis of 17 randomized controlled trials. Among the 823 patients included in the final analysis, individuals reported: 1) intensity of joint pain (with or without swelling), 2) morning stiffness, and 3) use of non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen. Analyses compared studies administering fish oil supplements for less than two months and greater than five months. Researchers classified a high dose as > 2.7 grams and a low dose as < 2.7 grams of omega-3s.



What Was the Outcome?

Research participants receiving higher doses of omega-3s reported significantly fewer experiences of painful joints than those receiving lower doses. However, the researchers point out that there may still be important effects at lower doses and more human studies are needed. Omega-3s have potential to improve pain outcomes (after three months duration), improve morning stiffness, and reduce NSAID use.

What Is the Optimal Dose?

This study evaluated doses ranging between 2.7 and 4.0 grams of omega-3s per day (EPA/DHA). Until more is known, however, high doses of omega-3s (> 3.0 grams per day from food and supplementary sources) should be consumed only under a doctor’s supervision. High doses can be dangerous among patients living with congestive heart failure and bleeding disorders. Suppression of inflammation may be helpful, but the possible effects of suppression of the immune system should also be considered. Always seek guidance from an experienced physician before starting any new medical therapy.

What Studies Are on the Horizon?

These scientists recommend a controlled clinical trial that uses 2.7 gram/day of omega-3s (EPA and DHA) for at least three months using a non-olive oil placebo condition. Keep an eye out for future studies that home in on the dosage and optimal analgesic effects of EPA/DHA in people living with arthritis and chronic inflammatory pain. ■

Original Reference: A meta-analysis of the analgesic effects of omega-3 polyunsaturated fatty acid supplementation for inflammatory joint pain. Robert J. Goldberg; Joel Katz, Pain. 2007;129(1-2):210-223.

From America to Traveling With IG Treatment

By Zachary Pugh

Nancy Hoffman dreamed of traveling to foreign lands where shimmering sunsets appear as a distant alien world across a warm green-beige canvas of silhouettes—à la National Geographic. She also dreamed of driving the crisscross highways of America in search of beauty and inspiration and the perfect place to sip a glass of wine.

Happily, Nancy's dreams, her vision of freedom, have become reality.



Nancy and Moe bask in the sun in Yellowstone National Park

Diagnosed with common variable immune deficiency (CVID) in 1995, Nancy, 64, successfully transitioned from eight years of intravenous immune globulin (IVIg) to subcutaneous immune globulin therapy (SCIg or SubQ). “[I] did IVIg for eight years, and now on SubQ for two,” she says. “I am still amazed after two years how incredibly good I feel, and what flexibility this gives me!”

Because of Nancy's new-found freedom, which she attributes to SubQ, traveling with treatment is no longer a hassle, and her self-administered IG treatment has given her the freedom to pursue her travels. “This process [SubQ] is so amazingly simple, and allows me the control over when and where I do my treatment. It gives me such incredible freedom.”

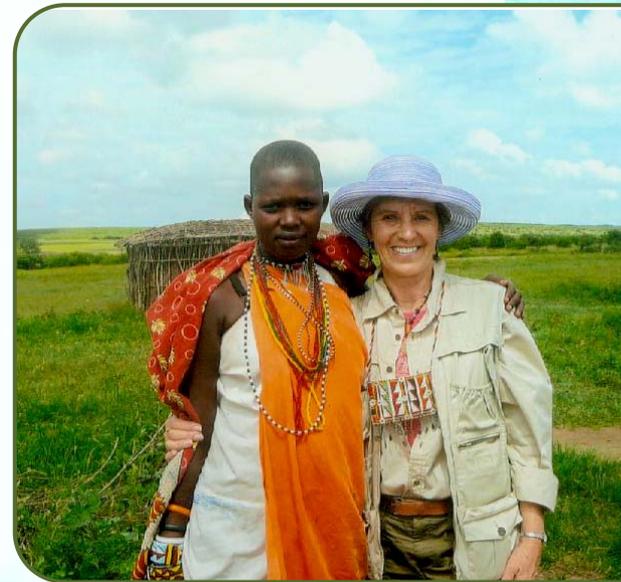
Just recently, with not a care in the world, Nancy and her husband, Moe, journeyed across America in their motor home. All the while, she was able to maintain her treatment schedule. “We toured 11 states ... saw five of the national parks, rode bikes in Colorado and attended the wonderful IDF conference in St. Louis for three days,” she says with a smile in her voice so enthusiastic that it's contagious. “I did my SubQ treatment each week ... and enjoyed the beautiful scenery, while my pump poured this wonderful juice into me!”

Nancy emphasizes that while it's easy and hassle-free, cleanliness while traveling with treatment is a must. “Of course cleanliness is important, and I was able to wash up in the bathroom, and use sanitizers to clean the kitchen table where I set it all up,” she says.

Africa



Nancy picnics with Baby Winnie at Nyumbani, the AIDS orphanage



Nancy befriends a Samburu tribeswoman

Now, if you think that traveling across 11 states and biking in Colorado while maintaining a proper SubQ treatment schedule is freedom, try Africa. Yes, that's correct: the cradle of life.

This past January, Nancy had the incredible, purely life-altering opportunity to work and tour in the small town of Karen, a suburb of Nairobi, Kenya. "[I] worked at an AIDS orphanage sponsored by the Kenyan Children

Foundation, which is the group I was with," she says. "We had wonderful experiences with the children."

While in Kenya, Nancy also had a chance to take two amazing safaris, one in Samburu, a rather remote area located in northern Kenya, and another in Masai Mara. "I not only photographed the most beautiful animals," she says, "I also visited a Masai village and toured their huts, and talked with the women about their lives and mine."

Because Nancy is a globe-trotting, independent woman, she takes the advice of her healthcare provider very seriously. In preparation for her departure for Africa, her doctor had some very important and practical advice. "Dr. Riedl encouraged me to take malaria pills and an extra supply of antibiotics ... drink bottled water and [eat] cooked food, and go for it!" she says, adding that she also consulted with other patients who travel extensively with treatment.

With this trip to Africa behind her, and many more road and globe adventures to come, Nancy has some important advice for those who are apprehensive about traveling with treatment. "I believe SubQ is life changing," she says. "It gives us the opportunity to live our lives to the fullest and follow our dreams." ■



On safari, Nancy spotted this lioness



IVIIG and Cancer:

By Lauren Gerstmann, MPH

When an oncologist told Helene Kelly that she had cancer, she was scared. Now she chuckles, "I didn't even know what an oncologist is."

With her diagnosis, Helene learned that she has chronic lymphocytic leukemia (CLL), an incurable blood cancer, but one with symptoms that can be managed indefinitely with a battery of treatments including intravenous immune globulin therapy (IVIIG).

Like Helene, many people are initially confused and overwhelmed when they learn they have cancer. Blood cancers that affect the immune system and may be incurable are especially frightening. This article will look at the role of IVIG in cancer therapy and will focus on the most common uses of IVIG: symptom management for adult blood cancers, such as CLL and multiple myeloma, and supportive therapy for pediatric leukemias and neuroblastoma.

IVIG and Cancer

Boosting the immune system is a routine part of cancer therapy, supported by the rationale that a healthy immune system can more effectively fight off the complications of infection. IVIG therapy specifically is routinely used as part of the supportive treatment for CLL and multiple myeloma.¹ CLL and multiple myeloma are incurable blood cancers, but their symptoms can be managed with several therapies including IVIG, and IVIG becomes a lifelong treatment. Both of these cancers attack blood cells that are involved in fighting disease, causing them to be called “blood cancers.” Blood cancers depress the immune system and make the patient vulnerable to infection, which is where IVIG can play its supportive role.

Helene was 54 when she was diagnosed in 2003. She hadn't felt right for some time, and then she experienced a terrible shingles attack that worsened despite treatment with antiviral medication. Helene was surprised when her doctor hospitalized her. She had been healthy and active her whole life. Lab tests immediately showed that she has CLL, the cause of her shingles. After a huge dose of chemotherapy that made Helene very ill, the doctor began her on IVIG to manage her symptoms. Helene switched doctors, and began seeing Dr. Robert Jacobson, the clinical research director at the Palm Beach Cancer Institute in Florida. Dr. Jacobson educated Helene about CLL and regulated her chemotherapy and IVIG treatments, making her more comfortable.

A Team Player with a Big Role

The key to understanding the role of IVIG in blood cancers is to recognize how these cancers affect plasma cells. Plasma cells develop from B lymphocytes (B cells), a type of white blood cell that is made in the bone marrow. Normally, when bacteria or viruses enter the body, some of the B cells will change into plasma cells. The plasma cells make a different antibody to fight each type of bacteria or virus that enters the body.² In CLL, too many lymphocytes are produced, and they can't fight infection well. Also, as the amount of lymphocytes increases in the blood and bone marrow, there is less room for healthy white blood cells, red blood cells and platelets, which can result in infection, anemia and easy bleeding.³

In multiple myeloma, the lymphocytes successfully transform to plasma cells, but the plasma cells are abnormal. Abnormal plasma cells (myeloma cells) build up in the bone marrow, creating destruction of bone and normal bone marrow. This in turn creates a cycle where the bone marrow can't produce the stem cells that are precursors to mature blood cells.⁴

CLL and myeloma primarily affect older adults with average onset in the 60s. Both cancers affect men more frequently than women. Both cause pain, fatigue and recurrent infection.^{5,6}

Once Helene finished her chemotherapy, she felt like a different, healthy person. Today, Helene is living well with her disease. Her lab counts have normalized, and she has much more energy. She attributes much of her renewed health to her maintenance IVIG therapy. Unfortunately, her local hospital stopped providing IVIG due to the cost, resulting in Helene missing two treatments of IVIG. She immediately contracted bronchitis that antibiotics could not touch. As soon as she resumed IVIG therapy in her doctor's office, her health improved dramatically. Now, she receives IVIG treatments at home every 28 days, and considers IVIG a comfortable part of her routine.

IVIG and Pediatric Cancer

According to Dr. Jerry Finklestein, a pediatric hematologist-oncologist at Long Beach Memorial Hospital in California, the state-of-the-art care for pediatric cancer is continually evolving. Ninety percent of Dr. Finklestein's eligible patients under the age of 14 are involved in a research protocol to learn more about, and to treat, their cancer. The inherent flux in treatment protocols makes it unsurprising that IVIG has a different role in pediatric cancer than it does in adult cancers.

While some debate lingers over the most effective use ➤

¹ www.emedicine.com/med/topic3546.htm

² www.webmd.com/cancer/tc/Multiple-myeloma-plasma-cell-neoplasm-Treatment-Patient-Information-NCI-PDQ-General-Information

³ www.webmd.com/cancer/tc/Leukemia-chronic-lymphocytic-Treatment-Patient-Information-NCI-PDQ-General-Information-About

⁴ www.webmd.com/cancer/tc/Multiple-myeloma-plasma-cell-neoplasm-Treatment-Patient-Information-NCI-PDQ-General-Information

⁵ www.webmd.com/cancer/tc/Leukemia-Topic-Overview

⁶ www.multiplemyeloma.org/about_myeloma/2.04.php

of IVIG in pediatric cancer, IVIG is used primarily short-term and in a supportive role. It is used to boost the immune function of pediatric cancer patients who have thrombocytopenia (platelet depletion) that has an autoimmune component, or it is used as a supportive therapy when cancer has mandated that a child undergo a bone marrow transplant (BMT). BMT is a front-line therapy for children with acute lymphocytic leukemia (ALL) and may be an early therapy for non-lymphocytic leukemia—both blood cancers. BMT and subsequent IVIG use are particularly indicated if risks are reduced by having a sibling match.⁷

IVIG also plays a supportive role in stem cell transplants after intensive cancer therapy. For example, neuroblastoma is a cancer that forms in nerve tissue of the adrenal gland, neck, chest or spinal cord. It usually affects children under 5 years.⁸ Because it often spreads to the lymph nodes, bones, bone marrow, liver and skin, it can have significant impact on the immune system. Some children with neuroblastoma receive treatment so toxic that it destroys their bone marrow. After their bone marrow is destroyed, it is replaced with the child's own marrow, which was collected and banked before treatment. IVIG is one part of the recovery process.

In all these situations, IVIG plays a supportive role in cancer therapy, rather than a curative role. But a rare complication of neuroblastoma provides a notable exception: Some children with neuroblastoma develop “dancing eye syndrome” (also known as opsoclonus-ataxia or opsoclonus myoclonus). Children with this complication have jerky eye movements and a wobbly gait (myoclonus). Even more significant, dancing eye syndrome can eventually have developmental and behavioral consequences.⁹ Dr. Finklestein explains that this may be the one area in cancer therapy where IVIG plays a curative role (in conjunction with other therapies such as ACTH, a pituitary hormone). Dancing eye syndrome seems to have an ill-defined immune component, and can be cured (or nearly cured) by treatment with IVIG.

Dr. Finklestein is banking on this treatment right now, giving one of his young patients IVIG infusions every four weeks, for six to eight months, in the hopes that her eyes will stop jerking and that she will resume walking normally.

IVIG & Cancer: Current Research

Who: GammaCan International

What: Investigation of the uses of IVIG in treatment of solid tumors and metastatic cancers

When: Currently a Phase II clinical trial that is still recruiting participants

Why: The researchers found that IVIG inhibited the metastatic spread of melanoma, carcinoma and sarcoma in mice

To learn more about this research or to contact the investigators, go to ClinicalTrials.gov, reference ID # NCT00294476.

www.clinicaltrials.gov/ct/screen/BrowseAny?path=%2Fbrowse%2Fby-sponsor%2FINDUSTRY%2FGammaCan&recruiting=true

Conclusions

The common theme in both adult and pediatric cancers is that IVIG may be used as part of cancer therapy when the cancer or its treatment has depressed the immune system. It is rarely a cure, but it can help a cancer patient remain strong to fight the disease.

The role of IVIG in cancer therapy may be expanding. Some researchers note a relationship between autoimmune conditions that are treated with IVIG and some cancers. For example, people with Sjögrens syndrome (an autoimmune condition causing dry membranes) are more likely to develop lymphoma; myasthenia gravis patients have an increased risk of thymoma, and some myositis patients may be at increased risk for lung and ovarian cancers.¹⁰

On the other hand, some cancer patients have an increased tendency toward immune system dysfunction (as seen with blood cancers that directly affect the immune system) and autoimmune reactions. A wide variety of cancers can cause elevated autoimmune antibodies, even if patients do not develop a full autoimmune disease.¹¹

Researchers at GammaCan International, a U.S.-Israeli company, are experimenting with the use of autoimmune antibodies in cancer treatment.¹² Noting the complex relationship between immune dysfunction, autoimmunity and cancer, and the widespread effect of IVIG on the immune system, these researchers want to see if they can extend the role of IVIG therapy to treat a wide variety of metastatic cancers. If they are successful, IVIG could move from being a trusty sidekick to being a star player in some types of cancer therapy. ❏

⁷ For more information on bone marrow transplant, please see “Bone Marrow Transplant: A Search for Health” in the August-September 2007 edition of *IG Living*.

⁸ www.webmd.com/cancer/tc/Neuroblastoma-Treatment-Patient-Information-NCI-PDQ-General-Information-About-Neuroblastoma.

⁹ Mitchell, WG, Davalos-Gonzales, Y, Brumm, VL, Aller, AK, Burger, E, Turkel, SB, Borchert, MS, Hollar, S, & Padilla, S Opsoclonus-Ataxia Caused by Childhood Neuroblastoma: Developmental and Neurologic Sequelae *Pediatrics* Vol. 109, No. 1 January 2002, p. 86-98.

¹⁰ http://testing.duess.ca/gammacan/download/ivig_prevent_tumor_review.pdf

¹¹ *Ibid.*

¹² *Ibid.*

Editor's note: To contact Helene about CLL and her treatment, please direct your message to editor@igliving.com. She is happy to share her experiences and to offer support to others with CLL.



Let's Talk!

By Shirley German Vulpe, EdD

If your life depends on immune globulin, this column is for you! It is an opportunity to network and share our experiences, because it behooves us to learn as much as possible about all of the ramifications of our illnesses. This column allows us to learn from one another. If you have a story you'd like to share, please email us at editor@igliving.com.

For this column, I interviewed Barbara Yodice, founder of the Autoimmune Information Network and a multiple autoimmune disease patient.

Shirley: Barbara, tell me a little bit about your illnesses.

Barbara: Sure. I was diagnosed with sarcoidosis when I was 17. I was essentially fine until I was about 25. Then I started to have all kinds of unusual difficulties: dropping things, difficulty swallowing, difficulty doing everyday tasks, such as fixing my hair. I went to many doctors. It was a very difficult time. I struggled a lot. After three years of searching for help, a neurologist made the diagnosis of myasthenia gravis.

Shirley: Rare conditions are difficult to diagnose?

Barbara: They sure are.

Shirley: What happened next?

Barbara: Well, in the following several years, I was diagnosed with five other autoimmune diseases.

Shirley: Wow, is that unusual?

Barbara: Yes, but more common than you might think. It appears that [people] with one autoimmune disease are also subject to developing more autoimmune diseases.

Shirley: How are you now? Have you found a successful treatment?

Barbara: I am better now than I have been in a long time. I attribute that to two medications: IVIG, which I take every six weeks—I have a port now and it is very easy

to administer—and low-dose naltrexone.

Shirley: It's great that you are doing well now, but it sounds as though you had your struggles!

Barbara: I sure did, and it was because of these struggles that I started our organization.

Shirley: The Autoimmune Information Network?

Barbara: Yes.

Shirley: You were unable to find the help you needed from other patient organizations?

Barbara: No, not everything. First of all, many of the rare autoimmune diseases have no national organization, such as stiff-person syndrome. I also found that the organizations I contacted... the people I talked to had no personal experience with the disease or many of the problems I was encountering.

Shirley: How is your organization different?

Barbara: Several ways. We provide immediate and direct individualized assistance to those who contact us. We find doctors and sources for obtaining insurance or paying for medication, help with disability claims, run local support groups, go to doctors with patients and provide expert witness testimony. We have provided computers for patients who have no way of getting online and one-time assistance, paying for medications until other resources we have referred

the patient to kick in. One hundred percent of the money donated to the Autoimmune Information Network goes to autoimmune patients who contact us. We have provided help for over 26,000 patients in 42 countries in the two and a half years we have been in operation.

Shirley: That is indeed exceptional. Who does all this?

Barbara: I work 60 to 70 hours a week on this. My husband and my sister both help a great deal also.

Shirley: With all of this experience, is there a message you would like to give to people?

Barbara: Yes, the importance of people donating blood. Most people have little awareness of how much they can help others by donating blood. I feel IVIG has saved my life and the lives of many other patients. Few realize that every dose requires more than 1,000 donations of blood. So encourage everyone who can to donate! ■

Resources

Autoimmune Information Network
PO Box 4121, Brick, NJ 08723
877-246-4900 or locally 732-262-0450
www.aininc.org

Myasthenia Gravis
National Institute of Neurological Disorders
www.ninds.nih.gov/disorders

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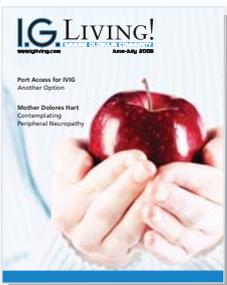
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ASK KRIS



Kris McFalls has two adult sons with chronic diseases treated with IG and is also on IVIG therapy herself. 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. Your confidential information will not be used for any purpose but communicating with you about your questions.

Reader: What is the association between omega-3s (specifically EPA and DHA) for inflammatory disorders? Then, what is the proper dosage and how safe is it, particularly for those with weakened immune systems? It looks promising but scientists were unable to recommend a certain dose, length of time or brands.

Kris: Terry Harville, MD, PhD, medical director of three laboratories at the Departments of Pathology and Laboratory Services and Pediatrics at the University of Arkansas for Medical Sciences, answered this reader's question. Please note that the doses Dr. Harville mentions are not recommended for any specific individual. Patients should check with their healthcare providers to determine the proper dosage of any medication.

Dr. Harville: Specific studies are wanting. Studies performed a few years ago demonstrated that people with rheumatoid arthritis or osteoarthritis could reduce by one-half their dosage of NSAID (non-steroidal anti-inflammatory) medication when they were taking 5 or 6 grams of omega-3 fish oil each day. For example, a dose of 500 mg could be as effective at 250 mg each day when the patient is also taking 5 or 6 grams of omega-3 fish oil each day.

More recently, omega-3 fatty acids have been used to treat high serum triglyceride levels. The new brand name is Lovaza™ (formerly Omacor™). The dose is 4 g

per day in divided doses, for this FDA-approved prescriptive medication.

The benefit of omega-3 fatty acids is their anti-inflammatory potential. This has been applied to a variety of autoimmune conditions, with variable degrees of success. Nervous system conditions, autism, inflammatory bowel disease, arthritis disorders, cardiovascular diseases, etc., are among those where success is claimed.

Omega-3 fish oil typically comes in 1 g capsules. The dosing for an adult is typically approximately 6 g of omega-3 fish oil each day in divided dosing, e.g., 2 capsules three times a day or 3 capsules two times a day. Each capsule contains 1 g of fish oil (eicosapentaenoic acid, EPA, from approximately 180 mg to 465 mg and docosahexaenoic acid, DHA, from approximately 120 to 375 mg or approximately 300 mg to 840 mg total per capsule, depending on the brand). To achieve significant benefit, some suggest at least 3,000 mg of total omega-3s are required each day, especially for some of the more severe conditions. Therefore, a capsule with more EPA and DHA per capsule means that more omega-3s will be ingested with fewer capsules. It is suggested effects will be noticed in a minimum of two months (this is the case for triglyceride reduction), but six months or longer may be required for some conditions.

Since the fish oils can cause you to burp and develop a fishy taste in the mouth, and may result in stools that have a fishy odor, one should begin with one capsule per day, increasing over a week or two, or even longer, to better tolerate the full dosing.

Side effects may occur. As noted, the fishy odor and taste may cause problems in some people. It is recommended that people with known allergies to fish or soybean should not take the omega-3s. ➤

ASK KRIS

People interested in omega-3s should discuss this with their physicians before taking them. Bleeding may occur more readily, so people on Coumadin, heparin (Lovenox™) or aspirin should use omega-3s only under the guidance of their physicians. The typical dosing adds 6 g of fat to the daily diet, which is 10 percent or more of the recommended daily fat intake for an adult, therefore other fat intake should be reduced accordingly. The increase in fat in the diet may affect diabetes, so people with diabetes should discuss the use with their physicians.

There are no studies that I am aware of looking at the effects of omega-3 fatty acids on people with weakened immunity. A quick PubMed search of "omega-3 and immunodeficiency" reveals that 34 articles are available. Perusing the titles and abstracts reveals several in which positive impact is noted and none that would indicate contraindication for use in someone with immune problems. Again, however, patients should discuss the use of omega-3 fatty acids with their physicians.

When thinking about use of omega-3 fatty acid supplements, one could consider that this could be similar to the diet of someone from cold water latitudes on essentially a "fish only" diet. Indeed, some speculate that this may have been important to the health of early Norse explorers and their successful explorations and conquests.

Cyrus: I have been suffering with neuropathy for five or six years and I have read that IVIG is generally effective only in the first 18 months. Second, I do not know how effective the treatment is for patients with extensive nerve, joint and muscle pain. Third, I have heard that IVIG gives only temporary relief. And finally, IVIG contains the antibodies of 10,000 to 20,000 people and I am not sure what other side effects I could develop. Thank you for the information you are providing to me. You guys are really amazing and wonderful people.

Kris: On a personal note, we know it is true that IVIG contains antibodies from thousands of people and it can cause reactions, but it is those antibodies that give the

relief patients need from their symptoms. In the case of my kids, it is the antibodies from thousands of people that give my boys protection from infections. I posed your questions to Dr. Todd Levine of Phoenix Neurological Associates.

Dr. Levine: The questions you ask are concerning the timing of IVIG initiation and how it might affect a disease that has been present for a long time. Finding an effective therapy is easier the earlier you start. However, if the nerve disease is caused by the immune system and if the disease is active, then IVIG will be effective at any time in your disease. In addition, if the neuropathy is progressive, then taking no therapy will surely result in continued worsening.

The IVIG is only effective as long as the antibodies are in your system, so, generally, from four to six weeks. However, the effects for most people are very long-lived, as long as you receive treatment every four to six weeks. Many physicians will try to transition you over to other immunomodulatory therapies once they know you have responded to IVIG.

Finally, IVIG is a human blood product and that might have some risks, but there are countless systems in place to be sure that no communicable diseases are passed through IVIG therapy.

So, in summary, if you opt for no therapy, things may worsen. The only way to know if IVIG will work is to try, but both you and your physician need to weigh the risks of the therapy against the potential benefits.

Denise: My son will be turning 18 soon and is currently covered under CHAMPUS Tricare (his father is retired military). Since this is a pre-existing condition and my son will continue to need IVIG, will he still be covered even if he's no longer attending school or will I have to find a different insurance carrier?

Kris: I did some Internet research and found the information below on the Tricare website.
www.mytricare.com/internet/tric/tri/tricare.nsf/EXT/TRCRBscs_Elgbly_1?OpenDocument&SC=TRICAREBasics~Eligibility

The Tricare programs are available to family members of active duty military service members and to military retirees and their dependents. These dependents include:

- Spouses
- Unmarried children under age 21
- Unmarried children under age 23 who are full-time students
- Stepchildren adopted by the sponsor

Those who are eligible must be listed in the Defense Department's worldwide, computerized database, the Defense Enrollment Eligibility Reporting System. The following are not eligible for Tricare benefits:

- Parents and parents-in-law of active duty service members or retirees
- People who are eligible for health benefits under CHAMPVA (Civilian Health and Medical Program of the Department of Veterans Affairs)
- People age 65 or older who are eligible for Medicare can receive Tricare For Life benefits.

You can also phone Tricare at:

Northern states: 877-874-2273

Southern states: 800-403-3950

Western states: 888-874-9378

Susan: Is testing for trough levels necessary for management of IG dosage? I am managed based on number of infections, how I feel, etc. Many other PIDD patients are managed by trough levels.

Kris: This question comes up often and it has been my experience that doctors vary a great deal on the response. I posed this question to Dr. Harville.

Dr. Harville: This is a great question. In the past, when lower dosing of IVIG or even IMIG (intramuscular immune globulin) was being used, it was important to know the trough value (serum IgG level) prior to the next dose, to help determine if the dose being given was sufficient and the interval of dosing was correct. With the lower dosing given at that time, patients were somewhat more likely to have some breakthrough infections, and the trough values

could be used to justify greater or more frequent dosing.

With further availability of IVIG during the past few years, and further studies, it has become apparent that a higher trough value is associated with fewer infections and complications, especially long-term problems with respiratory diseases. Therefore, many physicians like to see the trough IgG level to near-normal (i.e., approximately 1,000 mg/dL), rather than greater than 400 mg/dL, as was common in the distant past.

How often should trough levels be measured? Perhaps once or twice a year for someone who is stable and infection free. Perhaps more frequently in growing children. In an adult who is infection free, after it is known that the trough is sufficiently high, further determinations may not be needed—assuming that the adult is hypogammaglobulinemic (i.e., IgG < 400 mg/dL) due to his or her immunodeficiency and trough determinations could be used to demonstrate achievement of better levels. For patients with dysgammaglobulinemia (i.e., initially normal, near-normal or even high IgG levels), trough measurements may not have much validity.

There is an important reason to measure trough values in younger children. Some young children will have delayed maturation of immunity and may have low IgG and IgA values for their age, with recurrent infections and poor recall antibody responses to immunization challenges. As these children grow, they may overcome the maturation delay and actually develop normal levels of IgG and IgA, as well as IgM. Therefore, following trough values and IgA levels in the younger child may reveal this process and actually allow for the discontinuation of IVIG therapy.

Therefore, monitoring the health of the patient is necessary, including the extent of infections, but trough values also appear to be important, especially for maintaining sufficient IgG levels to help prevent long-term problems in patients with hypogammaglobulinemia. ➤

ASK KRIS

Jennifer: I have a few questions:

1. Do PIDD patients tend to have a lot of depression at times?
2. Does immune globulin tend to make people retain water easily? I seem to do so every month, and I do watch my salt intake a lot. Crazy body!
3. In what other ways can immune globulin make the body react negatively?

I am feeling frustrated with a body that doesn't always cooperate. I do like the SubQ every week, and having it on my own schedule. That is one good thing!

Kris: I asked immunologist Dr. Richard Schiff, global medical director for Baxter Healthcare, to address your questions. I want to thank you for bringing up the issue of depression. I hear about this frequently, but too few patients are comfortable discussing it with their physicians. This information will certainly help other readers.

Dr. Schiff: I don't know of any specific studies of depression in PIDD patients, although surveys do indicate a fairly high rate. This is true for most chronic illnesses, but I don't necessarily think it is specific to immune deficiency. However, infection and autoimmune diseases do alter cytokine profiles and can make people feel tired or depressed. Situational depression responds to the usual medications. Otherwise, it is worth a close look for subclinical infection and autoimmune disease to be sure they are not contributing.

I don't know of any studies that show that immune globulin causes water retention. Gammagard S/D has a lot of salt and can transiently cause fluid retention, but it should only last for a few hours. It should be less apparent for SubQ because less is given at a time. Water retention suggests hormonal imbalance.

The last question is too nonspecific to be answered. If a patient has an infection, the IVIG can react with the germs and cause a reaction—fever, chills, fatigue, etc.—similar to having the flu. These symptoms often improve as trough levels rise and infections are better controlled. SubQ dosing should help but not if absorption is not as good. It is worth checking levels and again, looking for signs of occult infection (e.g., sinusitis).

Kris: Please remember, before making any changes to your treatment, you should always seek the advice of your personal physician.

Jennifer responds: I don't think the depression is product-related, but I do know that I haven't been getting enough uninterrupted sleep for so long that it is putting my body under stress! So I try to take naps. ... You are really a godsend in my life right now! It is hard to talk to people who don't have a clue about how life is for you. They just give you the sympathy thing, but no understanding. Or they make you feel like you are totally germ-loaded and will get them sick! Are we really that contagious to others?

Kris: First of all, always ask for a copy of your blood work, and keep a binder with copies of any lab work you've had done. Then you and your doctor can notice any trends, and, if one day something does show up in the abnormal category that has been slowly moving that way, you are not taken by surprise and can talk with your physician regarding any concerns you may have. Also, if you have copies of all your lab work, you always have what you need if you see a new doctor.

As far as being contagious, my kids' physicians tell me others are far more dangerous to us than we are to them. I just don't think well-meaning people know what to do or say at times. It's a matter of educating them and understanding our own limits. The most important coping mechanism I have found is to have a sense of humor. There is no better medicine than laughter and a good friend.

Last, interrupted sleep over time can increase stress and be an indicator of depression. Try doing a Google search, and you'll find a lot of information on this topic.

Andy: I have checked into international health insurance companies for a long-term stay out of the country. So far, the only company that indicates it will cover me will probably cost nearly \$6,000 per year. This isn't entirely out of the question, but I would then face the problem of not having had any coverage in the United States for one year, so, when I return, I will have lost my pre-existing condition status.

Kris: I asked a reimbursement advocate with a national patient organization if your international insurance would be considered “credible coverage.” Credible coverage protects you, upon your return to the United States, from being categorized as having a lapse of coverage, which would require your going through pre-existing clauses. The reimbursement advocate’s response follows:

Response: Many insurance companies based in the United States offer international insurance. As long as the coverage Andy has found for an international plan is with a reputable, U.S.-based company that documents in writing that the plan is considered “credible coverage,” he should be fine. However, I would be very leery of any insurance company that I never heard of, and Andy should forget about the discount health plans that have recently gained some popularity. These plans are not considered credible coverage.

Suzanne: I’m trying to find out the side effects, if any, of IVIG.

Kris: This is a common question, so we try to address it as often as possible. Another reader recently asked specifically about infusion rate-related reactions, so I’ve asked my friend who is a pharmacist and IVIG expert to respond to both readers.

Response: Every patient is an individual when it comes to side effects to IVIG. Some patients can tolerate all brands of IVIG while others may only tolerate one or two. Most side effects occur with the first dose of IVIG, and for that reason first doses should always be given under a controlled setting. The rate of administration of IVIG can also be critical to reducing or eliminating side effects.

The good news is that most patients do not experience significant side effects to IVIG treatment. The most common side effects seen during an IVIG infusion are headaches and hypotension (low blood pressure), although hypertension (high blood pressure) can also occur. These reactions can be immediately managed

by slowing the infusion rate. In fact, these side effects usually help determine how fast an individual patient can be infused with each particular brand of IVIG.

Flu-like symptoms and malaise can also occur after an IVIG infusion. These can usually be treated by administering acetaminophen, aspirin or non-steroidal anti-inflammatory agents prior to and after each infusion. Some patients develop a tolerance to these side effects over time. If the side effects do continue to be a problem, a slower infusion of IVIG might resolve them or the patient can be switched to another brand of IVIG.

Rashes can occur with IVIG and are usually seen during the infusion, although sometimes they occur after an infusion. Rashes are treated with antihistamines or a corticosteroid, which can be added if the rash is more severe. If prophylactic treatment with antihistamines does not prevent recurrence of rashes, the patient can be switched to another brand of IVIG.

Severe post-infusion headaches, similar to migraine headaches, are an annoying side effect of IVIG infusion. Such headaches are considered to be aseptic meningitis and do not respond well to medications given either before or after an infusion. Some clinicians have experienced positive results with medications used to prevent and treat migraine headaches, although there is little confirmation of this in the published literature. Administering the immune globulin subcutaneously has been shown to benefit patients who experience these headaches or another brand of IVIG can be tried. A third option is to administer the IVIG infusion over a long period—12 to 24 hours—using an ambulatory infusion pump.

More serious side effects are less frequent and most commonly occur with the first infusion of IVIG or after switching to a different brand of IVIG. One of these less frequent side effects is a violent shaking syndrome similar to that seen with patients who are administered Amphotericin B. Another side effect is a severe back and leg pain syndrome that patients describe as excruciating. Treatment for both of these syndromes involves the administration of intravenous antihistamines, steroids and narcotic analgesics. When treated ➤

ASK KRIS

quickly, these side effects can be easily managed, and, in some cases, the infusion of IVIG can be resumed. Patients can be premedicated prior to subsequent infusions or switched to another brand of IVIG. Interestingly, patients do develop a tolerance to these side effects rather quickly and in many cases it is not necessary to switch brands of IVIG, although switching brands is most often done to ease the patients' concerns.

Anaphylactic reactions, also infrequent, can occur with IVIG infusions. An anaphylactic reaction typically starts with a patient complaining of tightness in the chest or throat and an increase in blood pressure. Unlike a true anaphylactic reaction, the progression of symptoms is much slower and can be managed prior to symptoms becoming more serious. Treatment with intravenous antihistamines and steroids can usually resolve this in a matter of minutes, and, in some cases, the infusion of IVIG can be resumed.

Two side effects to IVIG are considered extremely serious: renal complications and thromboembolic events. In the case of renal complications, most of the reported cases were with IVIG products that contained sucrose. Only one product containing sucrose is currently available in the United States (CSL Behring's Carimune® NF). Additionally, most of the patients who experienced renal complications had risk factors, such as advanced age, diabetes or prior renal problems. In the case of thromboembolic events, the specific IVIG risk factor is not clear, although sodium content may play a role. Again, patients who had risk factors for thromboembolic events, such as coronary artery disease,

prior strokes or prior blood clots, were most at risk. A slow infusion rate or avoidance of high-risk IVIG products in these high-risk patients is warranted.

Subcutaneous immune globulin administration is safer in these patient populations.

Rhonda: How is chronic inflammatory demyelinating polyneuropathy (CIDP) diagnosed? Is there a test that results in a definitive diagnosis? Can a definitive diagnosis be made without a nerve biopsy?

Kris: I again prevailed on Dr. Levine, and he provided the following answer.

Dr. Levine: CIDP is a very difficult diagnosis to make. There are certain research criteria for the diagnosis that are highly specific, but may miss many patients who have the disease.

In general, the most helpful tests are the nerve conduction studies. These tests can make the diagnosis without the need for the nerve biopsy or spinal fluid analysis. In some cases, however, the nerve conduction studies may not be definitive, and, therefore, a nerve biopsy or spinal tap can be performed to help support or refute the diagnosis.

In some cases, even with all of this testing, the question may still be whether or not a patient has CIDP. In these cases, if the symptoms are severe enough, a neurologist may choose to try to treat a patient with IVIG or steroids for a few months to see if there is improvement. ■

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

The Skin We're In: Scleroderma

By Zachary Pugh

Imagine that your fingers feel like stone and your toes, ice. They look and feel foreign, white and discolored. Your face is hardened, the skin taut around your eyes, cracking in the creases where your lips meet. And inside, your esophagus begins to narrow, constricting your breathing to a slight wind that whistles like a thousand wasps. It's even hard to swallow the smallest meal.

These are only some of the symptoms that accompany scleroderma, a rare and chronic autoimmune disease that involves excessive deposits of collagen in a person's skin and, in many cases, other organs. Although the condition sounds debilitating, approximately 300,000 Americans do successfully live with it, treat it and persevere.

Understanding the Condition

The condition literally means *hard skin*. Although the symptoms vary greatly between patients, there are generally considered to be two major classifications of the disease, localized scleroderma and systemic scleroderma, which are broken down into three forms.

1. **Morphea scleroderma**, the least severe form of the disease, commonly affects or hardens isolated patches of skin.
2. **Limited scleroderma** progresses slower and usually has a positive prognosis. Internal organs are not as affected as in diffuse scleroderma. Hardening of the skin is usually limited to the face and hands.
3. **Diffuse scleroderma**, the most severe form, is systemic with extensive skin and internal organ hardening.

Scleroderma Treatment

Although there is no cure for scleroderma, there are many different therapies that are used to treat its symptoms. According to the Scleroderma Foundation, patients may opt for medication that decreases overall immune system activity, but because of the wide range of symptoms that accompany scleroderma, the prescribed method of treatment differs from person to person.

There is some evidence that intravenous immune globulin (IVIg) can increase the healing process of the various symptoms associated with scleroderma although it is not traditionally used as a treatment. In their 2004 article, "Efficacy and Safety of Intravenous Immunoglobulin for

Immune-Mediated Skin Disease," Anita Rutter and Thomas A. Luger of the Department of Dermatology at the University of Münster in Germany reported a "significant clinical improvement" with the use of IVIg combined with prednisone in a patient. Further, "[a]fter ten IVIg courses the patient showed a remarkable improvement of the skin lesions and esophageal dysfunction."

Despite this evidence, IVIg therapy for scleroderma is still considered experimental.

Living With Scleroderma

Diagnosed with limited scleroderma in 2000, Lyn-Li Torres has since undergone varying lifestyle transformations. "I have experienced many different treatments, both traditional and nontraditional. The most important thing I have learned so far is to trust my body's wisdom above and beyond all else," she says with a smile. "My body's ultimate goal is to heal and balance itself," she adds. "The answer lies in giving my body the space, love and nurturing it needs in order for this healing to occur. This, for me, means rest, lots of stretching, meditation, eating right and being creatively engaged," she says.

"A good, hearty laugh every day also helps! Ultimately, no one can heal myself but me—and I believe that is what I am doing with every thought that I choose to have!" ■

For More Information

Scleroderma research is ongoing, and the details of this enigmatic condition continue to evolve. To read more about scleroderma and scleroderma research, visit the following websites.

Johns Hopkins Scleroderma Center
scleroderma.jhmi.edu

Scleroderma Research Foundation
www.srfcure.org

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IG Reimbursement



By Michelle Vogel, MPA, and Kit-Bacon Gressitt

Loss of Coverage for Off-label Use of IVIG

Simone of California has multiple sclerosis (MS) and has been treated with IVIG and covered by her current insurance company for almost four years. Given her other diagnoses, no other MS treatment is available to, or effective for, Simone. IVIG has allowed her to continue to work despite her illness; without it, she would be disabled.

Simone's insurer recently determined that IVIG therapy was considered an experimental treatment for MS, and her coverage for the treatment would be discontinued.

Simone appealed her case but lost because of her insurance company's determination that MS is not a covered diagnosis for IVIG.

Many private insurers are using Medicare coverage determination guidelines—or even more restrictive guidelines—to limit both IVIG coverage for patients and the insurers' financial liability for off-label uses of IVIG. Such determinations are most often based solely on medical literature.

However, the research reflected in medical literature does not accurately represent the full range of individual patient response to IVIG therapy, and insurers are not always aware of available supportive literature. Consequently, for patients with MS and other off-label IVIG uses, the trend toward reliance on medical literature for local coverage determinations is proving devastating to their health and functionality.

Because of Simone's insurance company's determination, she has been paying for her IVIG therapy. However, she cannot afford to continue her treatment, and she is not eligible for her manufacturer's assistance program because she did not sign up for the program when she first began using its brand of IVIG and because she is using IVIG for an off-label condition. She is pursuing the appeal processes to challenge this coverage determination.¹

What should you do if you are in a similar situation?

1. Always appeal your case and follow your insurer's appeal process to the letter. Any deviation, such as a missed deadline for a step in the process, is cause for denial. Read your coverage determination carefully so you can fully understand what is being denied, why, what you must do to appeal, and when. When mailing in your appeal, request a return receipt at the post office, so you have

proof it is received on time.

2. The following information may be helpful to file with your appeal: a letter from your treating physician explaining why the IVIG treatment is necessary; all your relevant medical records, including documentation of your diagnosis; any evidence documenting that IVIG has been beneficial especially if there is any clinical evidence; medical journal articles that document effectiveness of IVIG for your diagnosis; any evidence documenting that other therapies have not been effective or that they would be harmful to your health.
3. Be prepared for the long haul. Most patients do not win their first appeals. Again, follow your insurer's appeal process explicitly and be persistent.
4. Request a case manager from your insurance company so you are working with one person who understands your case.
5. Contact the national patient organization for your disease state (see the *IG Living* Resources section, beginning page 43). The information you share about your case may help another patient.
6. If the patient organization cannot help you, contact *IG Living* to request reimbursement advocacy assistance. You can send in a request from the magazine's website, www.igliving.com, or by calling the editor at 800-843-7477.
7. You can also request assistance from your congressional representative through his or her local district office. If you do not know who your elected representatives are, visit www.igliving.com, click on "Take Action!" Then click on "Contact your representatives today!" and enter your ZIP code.
8. Review the reimbursement materials on the Neuropathy Action Foundation website. Go to www.neuropathyactionfoundation.org, click on "Patient Resources and News," then click on "Fight Your Insurance Company" and read the entire page—it's good advice.
9. Some IVIG manufacturers offer programs that give patients "credit" for every time they infuse the manufacturer's IVIG product. Then, if a patient loses insurance coverage for IVIG treatment, the credits can be used to obtain IVIG from the manufacturer for a period of time. When you begin IVIG treatment, contact the IVIG manufacturer to determine if this type of program is offered and sign up immediately.

¹ See the *IG Living* article "Medicare Local Coverage Determinations Limit Access to IVIG" in the April-May 2007 issue for more information about such restrictions.

Hunter of Texas has an extremely rare condition, stiff person syndrome (SPS), and his IVIG therapy was covered by his private insurance company, despite its being an off-label treatment for SPS. When he transitioned to Medicare, his physician told him Medicare will not cover IVIG for his diagnosis. Hunter would like to know if he has any options, and the answer is yes.

In Texas, local coverage determinations by Medicare contractors indicate that IVIG treatment for stiff person syndrome can be covered, but an individual case review is required. To support a successful case review, Hunter's physician must complete a prior authorization request form and document that IVIG helped improve Hunter's condition when he was covered under private insurance. Additionally, including in the review any medical journal articles that support the use of IVIG for SPS will increase the likelihood that the local Medicare contractor will approve coverage of Hunter's IVIG therapy.

Medicare Billing Codes for IVIG

Kristine of Arizona has a primary immune deficiency called polysaccharide antibody disorder, a selective antibody deficiency. She began IVIG therapy in December 2004, and her insurer, United Healthcare (UHC), approved coverage for treatments in her immunologist's office.

In April 2007, Kristine's immunologist reported that his contract with UHC had been reduced, affecting his reimbursement, and he could no longer treat her in his office. He transferred Kristine to homecare treatment, but she was subsequently informed by UHC that IVIG is considered experimental for her diagnosis. What happened?

The transfer from one site of care, the physician's office, to another site of care, Kristine's home, triggered a review by UHC. Case reviews are cause for concern for patients, because insurers' application of IVIG therapy criteria is increasingly restrictive.

Kristine's situation is even more challenging, because her type of primary immune deficiency, polysaccharide antibody disorder, does not have a specific diagnostic code, and Medicare recognizes only five specific primary immune deficiency codes for the homecare reimbursement, despite there being more than 120 recognized primary immune deficiency diseases.

When Kristine received her denial letter from UHC, it stated, "The clinical evidence in the current published peer-reviewed medical literature is insufficient to show that IVIG is an effective treatment for IgG subset deficiency in the clinical scenario. Therefore, IVIG is not a covered benefit."

Kristine is in the process of appealing this denial, and following is some of the information she should include in her appeal:

1. Her physician should emphasize that IVIG is a U.S. Food and Drug Administration-approved treatment for primary immune

deficiency diseases. The FDA approval is not negated by Medicare's lack of a specific diagnostic code for Kristine's particular primary immune deficiency.

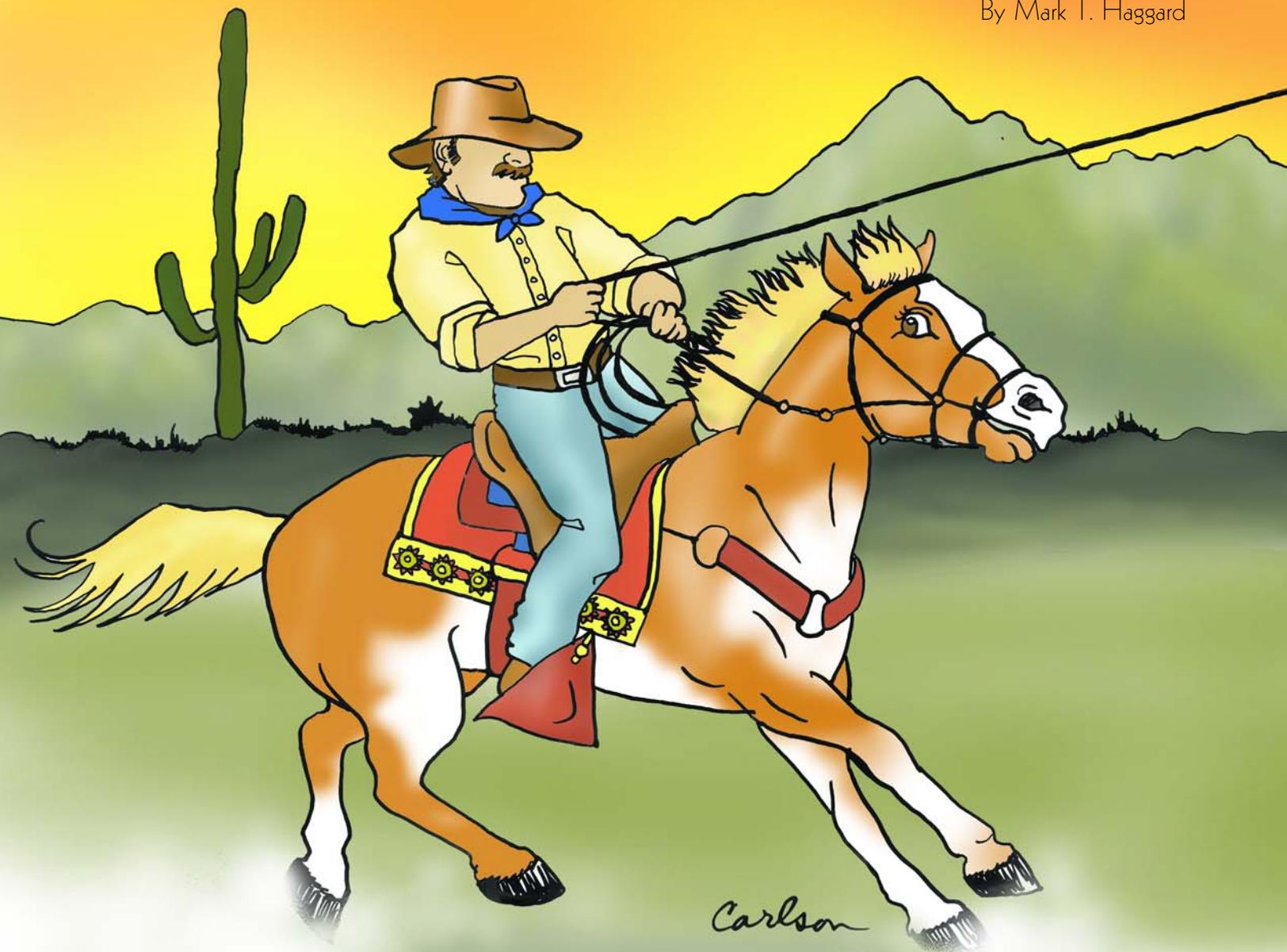
2. The April 2006 Journal of Allergy and Clinical Immunology article, "Use of intravenous immunoglobulin in human disease: A review of evidence by members of the Primary Immunodeficiency Committee of the American Academy of Allergy, Asthma and Immunology," supports treatment with IVIG for selective antibody deficiency. Kristine should reference this article in her appeal.
3. Additionally, the American Academy of Allergy, Asthma and Immunology states: "Patients who have normal total IgG levels but impaired production of specific antibodies, including those with isolated deficient responses to numerous polysaccharide antigens after vaccination, can present a diagnostic challenge. IgG replacement therapy should be provided when there is well-documented severe polysaccharide nonresponsiveness and evidence of recurrent infections with a documented requirement for antibiotic therapy. Further evidence of infection, including sinus and lung imaging, complete blood counts, C-reactive protein measurement, and erythrocyte sedimentation rate determination, would support the need for IGIV supplementation. In this setting, IGIV therapy is appropriate for patients with difficult-to-manage recurrent otitis media with risk for permanent hearing loss, bronchiectasis, recurrent infections necessitating intravenous antibiotics, or multiple antibiotic hypersensitivities that interfere with treatment."
4. The appeal should emphasize any aspects of Kristine's clinical history that are consistent with the above indications for the treatment of selective antibody deficiency with IVIG therapy.
5. A letter from Kristine's treating physician in support of the medical necessity for her IVIG treatment.
6. Any previous IVIG therapy coverage approvals, even if they are from different insurers.
7. A copy of the package insert or label from the IVIG Kristine uses: It lists the diseases for which IVIG is an on-label indication, including primary immune deficiency diseases.

Comprehensive documentation is an important element of a successful appeal, so all communications with your insurer should be in writing, whenever possible, including your request to appeal a determination. Even phone conversations with insurer representatives should be documented: Write down the date and time, name of the person(s) with whom you spoke, his or her title, his or her phone number, and important details of the conversation.

Finally, do not accept a denial of coverage without appealing. If you are unsure of what to do, contact *IG Living*. We are here to help! 📧

Saddling Up Anyway

By Mark T. Haggard



"Oh no," I muttered walking into my son's bedroom. "I know that smell."

"I'm sorry, Dad. I didn't make it to the bathroom."

"That's all right, Son. Let's take your stuff down to the washing machine."

This was not all right. Our daughter spent three days in

the hospital three years ago when rotavirus made its way through the community. Her flushed skin, listlessness and refusal to drink struck fear in our hearts of her becoming dehydrated. When an entire wing of a hospital has rotavirus, the results can be staggering. The most overwhelming effect is an incredible stench, which seems to



emanate from the pit of hell itself. We lived through it once, now we were living it again.

And the timing couldn't be any worse.

After a long vacation I was heading back to work, and my wife was left to handle the laundering, the Lysoling and the worrying.

This was not unusual though: Bugs and viruses seem to know when the end of summer is coming, and every year my kids get sick in the middle of August. It's the same hazy heat and different mutant bacteria to greet the crazy start of each school year.

I gave some thought to our medically fragile situation as I watched my wife scour the toilet for the umpteenth time.

As a history teacher, I often rely upon "The Code of the Cowboy" and its lighthearted proverbs to help me with hormonal 14-year-olds. I thought to myself, *If a cowboy can survive the wild frontier without modern day amenities, maybe they can relate to parents of kids with PIDD.* So come along, lil' doggies! This is what I came up with.

- "Courage is bein' scared to death and saddlin' up anyway." The dawn of every new day may greet us with the smell of biscuits n' gravy on the stove or the stench of rotavirus oozing from the outhouse. As PIDD parents, every morning has the potential of a new medical terror, but we saddle up anyway. We have to.
- "When yer ridin' through hell, you keep ridin'." Raising children with a chronic medical condition is, at times, like a ride through hell. It is gut-wrenching to watch your kids fight the needle stick for their IVIG or a blood draw. Hellish human experiments like the sweat chloride test for cystic fibrosis separate men from boys. The seven volts of electricity surging through my infant son's body would have brought John Wayne to his knees.

Caleb just kept in the saddle. However, as parents we know these procedures save our kids' lives. So we, just like our brave kids, keep on ridin'.

- "Ride for yer brand." Our family is our brand, and conquering this disease is the driving force. We must do all we can for our families and community. Our quality of life depends on it. If we don't sacrifice and advocate, no one else will.
- "Do what has to be done." We often know what has to be done, but sometimes we hesitate. So, when our physician recently handed us a stool sample kit for Caleb, we cringed. If the smell of rotavirus was about as close to hell as we'd ever want to be, what were we to make of actually handling the Devil himself? We do what has to be done, that's what. Our kid's diagnosis, recovery and possible cure depend on us doing the unimaginable.
- "Don't drink downstream from the horses." When you are collecting the aforementioned stool sample, make sure you use the recommended safety procedures. They just might save your life and your bowels. I found myself flat on my back with rota, and my wife soon followed. As she was heading into the sunset of her infection, she said, "It's just too bad the only thing we've been able to share with each other of late is the love of having indoor plumbing."

OK, so maybe those old cowboys didn't have to deal with the daily grind of being the parent of a chronically ill child, but I find their wit and wisdom refreshing. So when they say, "Don't squat with yer spurs on," consider yourself warned. When you're down with rotavirus, that's some darned good advice. 🍷



Multifocal

By Zachary Pugh

Your hands are weak and your legs twitch with involuntary movements. It's not the same weakness that follows you home from the gym after lifting weights. It's a wasting weakness in your hands, in your fingers, in your wrists that depletes your strength like a massive black hole. It's a weakness that never ceases, and the twitching and cramping never let go. This weakness, these involuntary contractions are your reality when you have multifocal motor neuropathy.

According to the Multifocal Motor Neuropathy Center at Johns Hopkins in Baltimore, multifocal motor neuropathy (MMN) is an immune disorder that is typically identified by "focal weakness" in different parts of the body, such as "wrist drop, grip weakness, impaired dexterity or foot drop. ... Only motor fibers are affected in MMN." People with MMN often experience weakness, yet typically do not experience other sensory symptoms such as numbness or tingling.

MMN was first described in 1985 as the result of the examination of four patients experiencing progressive weakness that resembled motor neuron disorders.¹ Often mistaken for amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease, MMN affects more men than women. According to an article in the 2006 European Journal of Neurology,² the factors that cause MMN have been narrowed down to motor conduction blockages.

Once associated with chronic inflammatory demyelinating polyneuropathy (CIDP), the medical community now considers MMN an entirely separate entity that is not related to CIDP. Unlike CIDP and other demyelinating neuropathies, studies indicate that patients with MMN show no signs of their condition improving or worsening when treated with steroids or plasmapheresis.³

¹ Parry GJ, Clarke S. Multifocal acquired demyelinating neuropathy masquerading as motor neuron disease. *Muscle Nerve* 1988; 11: 103-107.

² N. Strigl-Pill, A. König, M. Schröder, H. Beranek, B.G.H. Schoser, M. Spaeth, D. Pongratz, W. Müller-Felber. Prediction of response to IVIG treatment in patients with lower motor neurone disorders. *European Journal of Neurology* 2006; 13: 135-140.

³ *Ibid.*

Motor Neuropathy

In a 1993 breakthrough patient study, "High-dose intravenous immunoglobulin therapy in multifocal motor neuropathy,"⁴ MMN patients reported improvement following intravenous immune globulin (IVIG) therapy, establishing the first known case of IVIG being used as an effective therapy for MMN.

In this study, first published in the journal *Neurology*, five patients with MMN were treated with high-dose IVIG "twice with 0.4g/kg IVIG for five consecutive days at a 12-month interval, followed by maintenance infusions up to six to 12 months." The four patients who possessed high levels of "anti-asialo-GM1 had a consistent clinical improvement starting three to 10 days after the first IVIG course." Moreover, although the effects of the treatment only lasted for an average of 20 to 30 days in three patients, one patient displayed complete recovery for 12 months without needing additional treatment.

The National Institute of Neurological Disorders and Stroke (NINDS) states that, although MMN has symptoms similar to ALS, MMN is treatable and "[a]n early and accurate diagnosis allows patients to recover quickly."

Because MMN symptoms vary greatly, treatment is solely dependent on the severity of symptoms the patients experience. According to NINDS, "some individuals experience only mild, modest symptoms and require no treatment." For others, if the symptoms warrant treatment, it "generally consists of intravenous immunoglobulin (IVIG) or immunosuppressive therapy with cyclophosphamide."

Studies have shown that muscle strength begins to improve within three to six weeks after the start of IVIG treatment and, according to NINDS, "Most patients who receive treatment early experience little, if any, disability."

IVIG has continued to be an efficacious treatment for MMN. In a September 2006 interview with *Routers Health*, Dr. Vinay Chaudhry, director of the Johns Hopkins Multifocal Motor Neuropathy Center, agreed with the use of IVIG for patients with MMN. "A trial of IVIG may be

justified in patients with progressive distal asymmetric weakness in a multifocal peripheral nerve distribution even if they don't have conduction block on nerve conduction studies."⁵

Janice's Story

Janice, an active 51-year-old nursing home activities director and recreation therapist, knows all too well the complexity of MMN and the debilitating effect it has on the human body. "Most of my weakness is in my arms and my hands. One side more than the other," Janice says. "It becomes hard to do everyday things."

Despite this, she still works full time and loves every moment of it. "[MMN] makes me tired. I tire easier than maybe other people. I have to work a little harder at finding creative ways to do things that people would take for granted," Janice says. "Especially being in the kitchen, cooking, getting dressed. ... I use some adaptive aids."

In Janice's case, misdiagnosis is no stranger. "I was originally diagnosed in 1983 with Lou Gehrig's disease, or ALS, and many people that have the diagnosis of MMN were originally diagnosed with Lou Gehrig's disease first. Obviously, I was very lucky because that isn't what I have. I walked around, however, with that diagnosis for about nine or 10 years."

Following a decade of thinking that she had Lou Gehrig's disease, Janice's diagnosis suddenly changed to a then virtually unknown condition called multifocal motor neuropathy. "I was sent to a specialist at the University >



⁴ Nobile-Orazio E, Meucci N, Barbieri S, et al. High-dose intravenous immunoglobulin therapy in multifocal motor neuropathy. Abstract. *Neurology* 1993; 43: 537-544.

⁵ Douglas, David. "Immunoglobulin May Be Useful in Multifocal Motor Neuropathy." *Medscape Today* from WebMD 15 Sept. 2006. 14 Aug. 2007 www.medscape.com/viewarticle/544634.

of Cincinnati who had heard that there was this disease that was just kind of classified at that time," she says. "It would have been about 1993 and multifocal motor neuropathy was very rare."

After being seen by the specialist, who conducted many tests, a conclusive finding revealed Janice's condition. "This neurologist that I was going to felt that I kind of fit the picture [of MMN], and did some additional testing. They found it because they found the antibodies in my blood."

Janice's treatment options at the time of her diagnosis ranged from prednisone to Cytoxan to plasmapheresis, but it wasn't until she started IVIG that she was able to live the way she wanted. "I've been doing IVIG for about 10 years. But prior to that, I've done every single thing else that you could possibly do according to whatever the protocol was at the time, so I've had many doses of chemotherapy," she says.

"When I first started [treatment], I was also on high doses of prednisone and they thought, at that time, combined with the Cytoxan, that would be the thing that would really help, and as it was, the steroids were not good," Janice says. "I haven't had to do that, thankfully, for many years and I've just continued on the IVIG."

In Janice's case, the proof that IVIG is an efficacious treatment is apparent to her every day. Initially, she used IVIG for two consecutive days about every five or six weeks and now Janice infuses it one day every four weeks. The only side effect she experiences is an occasional headache, although she did have one startling experience when she switched brands. "I have had a life-threatening reaction when they switched brands, and that was a couple of years ago," she says, adding that since then she's continued to use the same brand and urges others to do the same.

"If I didn't have the IVIG, I wouldn't be doing anything. I'm quite sure of it. I could not live without it," Janice says.

Janice has some advice for those living with MMN. "The thing that helped me is that I've tried to really be my own advocate and stay on top of it," she says. "I think knowledge is power, truly."

Holly's Story

Much like Janice, Holly, 59, shares the same tale of a "mystery disease" and the misdiagnoses that inevitably followed. "I have been extremely frustrated for the past three years," she says. "It took about two and a half years and I finally got diagnosed in November."

For Holly, the symptoms came on strong and unexpected. She says that one day she woke up feeling very disoriented and sick. Thinking that it was not a serious problem, she went out to the local health food store and stocked up on vitamins, hoping to regain her health. "I dealt with it for a couple of weeks, went out and got some more vitamins. It just wasn't going away," she says. "I went to my doctor and they did an MRI of my brain."

With the exception of a small white spot on her brain, which her doctor surmised was the result of a vitamin deficiency, the MRI appeared to be normal—no alarming red flags.

Then, one day, Holly and her husband were hiking, when things took a sudden turn for the worse. "When I came down to the flat ground to go to the car, I noticed that I was limping. I had a very exaggerated limp and my husband asked,

'Did you pull a muscle or something?' I said, 'No, I don't have any pain at all, I don't know what's going on.'"

It was clear Holly needed to take action right away. She went back to her doctor and had another MRI done: still nothing. "Everything was fine. They took it from a different section of my brain. And everything looked OK."

Eventually, Holly was referred to a neurologist, but test after test and, subsequently, neurologist after neurologist, Holly saw no relief. Her condition could not be explained.

It wasn't until Holly was referred to Scripps in San Diego that a seemingly conclusive diagnosis was finally made. "He diagnosed me with Lou Gehrig's disease. Of course, my life just came absolutely crashing down around me."

After this devastating news, she was referred to an ALS specialist in San Francisco who had some interesting news for Holly. "He put me through testing and said, 'You know, I don't think you have ALS. What I think you have, and I can't be sure, is multifocal motor neuropathy. The symptoms are very much like ALS except it doesn't attack your heart or your respiratory [system].'"

Holly then began IVIG treatment on the recommendation



of her physician. “After four days, I noticed that some of the pain that I was having in my leg—almost like a really strong muscle cramp—did feel a little better, but when I went back up to San Francisco, about three months later, my symptoms had not gone away. And at that time, [the ALS specialist] said, ‘I don’t suggest that you go through this again. I just don’t know what else to do for you. There really isn’t a lot more research.’”

Holly continued weekly IVIG treatments for 16 weeks, but had unpleasant side effects. “I was literally in bed and I couldn’t get up. I had a migraine headache. I was shaking. It was pretty bad. Then after that fifth day, I finally started to get my strength back a little bit and the headache started subsiding.”

At that point, Holly decided to take control and she asked her physician about the Mayo Clinic. “I was really needing someone to tell me what I had. I was just tired of being in limbo and not really knowing. Last November I went to the Mayo Clinic in Scottsdale and went through testing again: EMGs, MRIs, all of that.”

After many tests, Holly was finally and conclusively diagnosed with MMN. “It was a professor of neurology there, Dr. Bosch. After four days of being there, he told me, ‘Yes, this is for sure what you have, multifocal motor neuropathy.’”

Holly understands that the rarity of her disease made her diagnosis difficult, and she believes the delay harmed her. “The problem is that it is such a rare disease that a lot of doctors have not seen it. That is why, I believe, I couldn’t get diagnosed. ... If I had been diagnosed [correctly] from the beginning, I wouldn’t be walking with a cane. If I had been treated with the gamma globulin earlier, I really believe that the situation wouldn’t be the same as it is right now.”

Because of her roller-coaster experience, Holly has become wary. “I went to so many doctors over these past three years, I have become very cynical, skeptical, whatever word you want to use,” she explains.

Still, Holly suggests that people actively seek out qualified physicians and medical centers such as the Mayo Clinic. While IVIG was not the answer for her, she does suggest that people should try it, but refrain from limiting their options. Most importantly, don’t lose hope if it doesn’t work, there are always other options out there. “My advice to someone is to definitely go to the Mayo Clinic, try the IVIG because it does work for a lot of people,” she says. ■

How can you learn more about MMN?

The first step is to consult your healthcare provider if you feel that you have this condition. Below are a few resources that provide information and support regarding MMN topics.

American Chronic Pain Association (ACPA)

Established in 1980, the ACPA was founded with the vision to provide resources for people coping with chronic pain. The ACPA is made up of hundreds of support groups throughout the United States—all dedicated to people who want to improve their quality of life.

www.theacpa.org

BrainTalk Communities: Multifocal Motor Neuropathy

BrainTalk is a global online community dedicated to enhancing the lives of neurology patients and their healthcare providers.

brain.hastypastry.net/forums/forumdisplay.php?f=193

Multifocal Motor Neuropathy Center (Johns Hopkins Department of Neurology)

The Multifocal Neuropathy Center, at Johns Hopkins Medicine in Baltimore, Md., provides a comprehensive clinical definition of MMN along with treatment options, FAQs and a detailed listing of current research and references pertaining to MMN.

www.neuro.jhmi.edu/MMN/index.html

National Institute of Neurological Disorders and Stroke (NINDS)

NINDS provides a working definition, current research and treatment options for MMN.

www.ninds.nih.gov/disorders/multifocal_neuropathy/multifocal_neuropathy.htm

The Neuropathy Association

Headquartered in New York City, N.Y., The Neuropathy Association was established in 1995 by people with neuropathy. Today the association is a nonprofit organization dedicated to helping those with conditions affecting peripheral nerves. The Neuropathy Association comprises 50,000 members and supporters, and approximately 120 support groups throughout the world.

www.neuropathy.org

Emmielou and Emla

By Cheryl Haggard

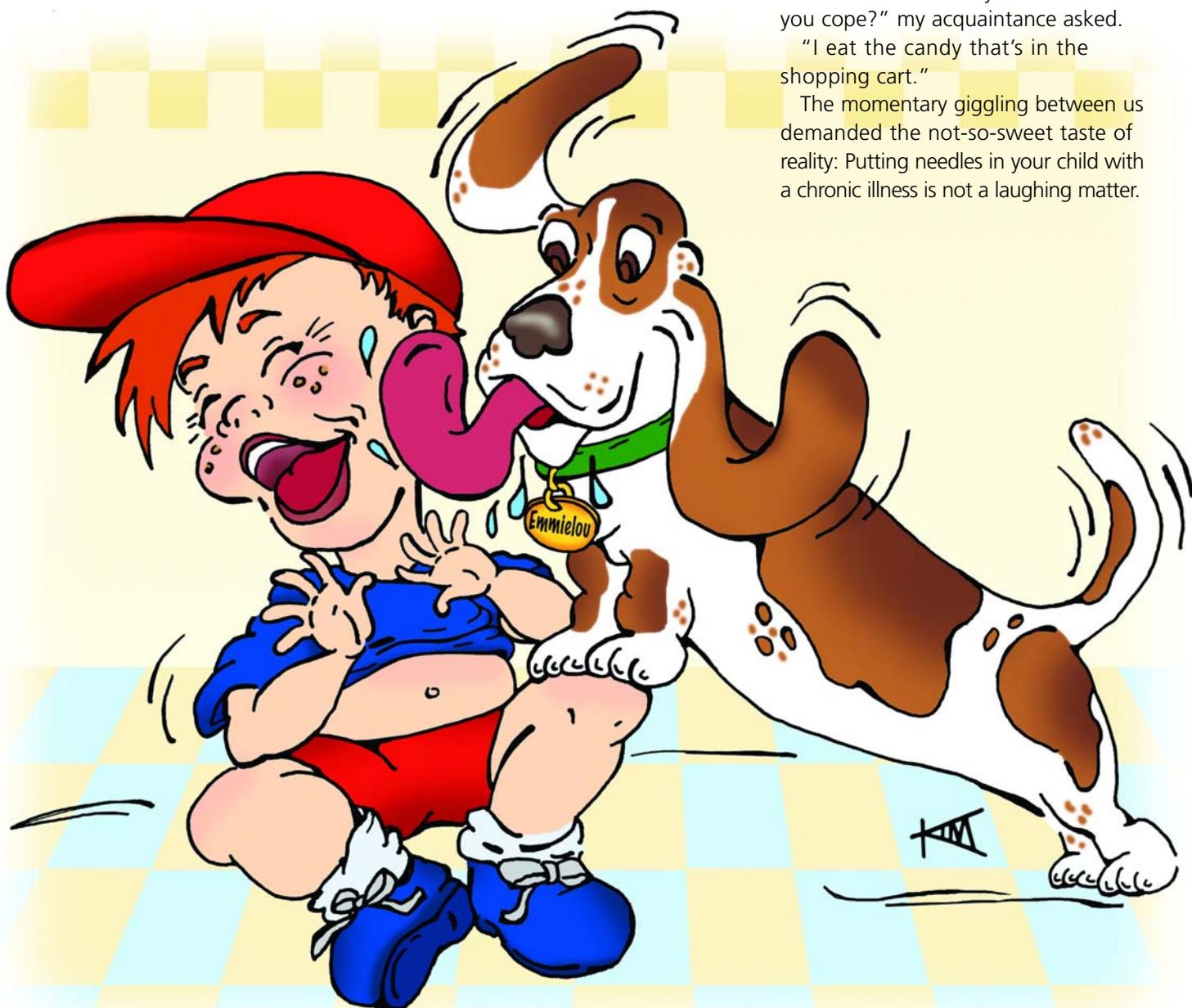
"So, how do you keep your kids from running away when someone is coming at them with an IV needle?" someone recently asked me.

"We buy them all the candy they can pack into a shopping cart," I replied with no regret.

"And what about you? How do you cope?" my acquaintance asked.

"I eat the candy that's in the shopping cart."

The momentary giggling between us demanded the not-so-sweet taste of reality: Putting needles in your child with a chronic illness is not a laughing matter.



In the April-May 2007 issue, I wrote about our beloved dog, George, and how he helps our children, Caleb and Molly, cope with the dreaded needle stick. After seeing Caleb through one more sinus surgery, George decided to grace the streets of heaven with the unconditional love of a chocolate Labrador.

When the time came for our PIDD kids' next monthly intravenous immune globulin (IVIG) infusions, Molly pierced my heart when she asked, "But how are we going to take our needles without George?"

The grieving process was still raw. It was just too soon for us to embrace a new four-legged friend and I, quite frankly, was enjoying respite from dog hair in my meatloaf.

I was sharing our doggie dilemma with my neighbor and jogging partner one hazy summer morning when she devised the perfect plan: "We'll bring Emmie over, and she can help with the kids' infusion day!"

Emmielou Prisbrey oozes basset hound beauty. Her trademark lopy ears and droopy eyes beg you to forgive her amazing drooling habit. Emmie's gentle whine will coax you to give her a treat: pigs' ears only for this poochly princess. And her fur, reminiscent of spilt chocolate milk, is oh so silky to the touch. More than once, I've caught my husband whispering, "You are such a sweetie," to her through the white picket fence that defines our property from the neighbor's.

As I got lost in Emmie being the perfect solution, I forgot that she's a licker. I mean this girl loves to stick her tongue on everything within reach. Instead of her basset branded beak, Emmie would rather use her tongue as her scent sensor. A walk around the block with Emmie is a three-hour gossip session about what her taste buds determine your neighbors have been buying the past week.

So, as the hour grew close for Caleb and Molly to get their IVIG, I gave Emmie her incomplete marching orders.

"You are not to drink out of the toilet, pee on the carpet or bark at strangers. You are to be as cute as a button, keep the kids occupied and comfort them when they get their needles."

Emmie graciously woofed at me in approval and went to town on her pig's ear treat.

When it came time to remove Caleb's Emla (the cream used to numb the skin before a needle stick), we called Emmie over to do her job. Emmie laid her overstuffed head on Caleb's shoulder and gazed into his eyes as if to say, "It's going to be all right, my boy, Emmie's here."

Maybe it was glass-shattering shrieks from my nurse or Caleb's uncontrollable laughter that took my attention away from the toaster catching on fire. Whatever it was, all I could focus on was Emmielou's lingua lapping up Emla off Caleb's port site.

"Emmie, stop!" we demanded in chorus. But it was too late. Emmie managed to sop up every last savory morsel of white gunk off Caleb's chest. When we realized that nothing could be done as Emmie's tongue held all the power, we laughed until we cried.

Then we panicked.

"What happens if Emmie's tongue goes numb?" I asked Nurse Nancy.

"I don't know, I guess we'll just have to wait and see," she replied as a giddy grin grew on her face.

As soon as I got off the phone with our veterinarian who convinced me Emmie's tongue would most certainly not fall out of her face, Nurse Nancy was following Emmie around with a rag attempting to keep stringy hound goo from adhering to the kids or their IV poles. After failing miserably, we decided to give up on Emmie's increasing amounts of drool and came up with a new reality show for cable TV: "What Will Emmie Slime Next?"

Emmielou ended her day with us with her chops full of pigs' ears and our apologetic explanation for the neighbors.

Thankfully, they laughed right along with us as the effects of Emla on Emmie didn't last long. We also concluded that we had officially redefined the age-old tradition of borrowing a cup of sugar from your neighbor. And I resolved that a shopping cart full of candy wasn't nearly as sweet as our Emmielou. ■

SCIG Administration: Learning to Do It Yourself

By Zachary Pugh

Before the United States had a licensed subcutaneous immune globulin (SCIG) product, the majority of people with primary immune deficiency disease (PIDD) were forced to schedule appointments with physicians, hospital clinics and homecare companies to receive intravenous immune globulin (IVIG) therapy from a nurse.

Since the Food and Drug Administration's licensing of Vivaglobin, an SCIG made by Pennsylvania-based CSL Behring, many patients are able to consider self-administering their SCIG at home.

But with the freedom of in-home self-infusion comes the need for healthcare provider and patient training on this administration method—and the need is significant.

Specialty pharmacy NuFACTOR, a homecare services provider and sponsor of *IG Living*, regularly receives requests from patients and providers seeking SCIG training materials.

IG Living has also been contacted by patients who were referred to homecare and shipped the SCIG product and supplies, but were given no training or, in some cases, inadequate training.

One young woman who contacted *IG Living* was spending 30 to 60 minutes each day attempting to administer Vivaglobin into muscle, a painful experience, rather than into subcutaneous fatty tissue. Without any hands-on training, she received the product and supplies at her home, and she was expected to figure it out for herself.

Another patient reported being trained at an outpatient infusion clinic and taught to lie down while infusing. Consequently, the patient was experiencing a lot of pain during treatment.

It is dangerous to administer any medication without proper guidance from a healthcare professional, and inaccurate or inadequate SCIG training results, for many patients, in a failed experience with SCIG. They often return to intravenous infusions, disillusioned with the promised freedom and flexibility of self-administered SCIG.

This is where SCIG education and training programs come in, and, although the resources are few, there are some available.

CSL Behring's training program, VITAL (Vivaglobin Integrated Training And Learning), was launched in April to educate patients and their healthcare providers about the proper methods for administering SCIG. The program focuses on at-home use of the product.

"We continually seek ways to ensure that consumers who use our products understand how best to use them. The VITAL program is an excellent example of that commitment," said Robert Lefebvre, vice president and general manager of CSL Behring's U.S. Commercial Operations.

The VITAL program provides physicians and nurses with guidance and a wide array of tools to help them educate their patients on SCIG administration. The program suggests that patients train with a nurse for several treatments before initiating their first independent treatment.

In addition to training materials for healthcare professionals, CSL Behring also provides patients with training tools for their own use, including a patient starter kit with an administration guide, information about the product and a treatment journal.

"One of CSL Behring's most important goals is to extend professional support and know-how well beyond the point of bringing high-quality therapies to patients," Lefebvre said.

NuFACTOR began developing its own SCIG training program before Vivaglobin was even available in the United States.

"We knew we were going to be a Vivaglobin provider," explained Sean Hubbert at NuFACTOR, "and we knew we would assume responsibility for assuring the nurses we work with and our patients are well trained. So, we jumped on developing our own comprehensive training program. Now, in addition to CSL Behring's training materials, we give our patients a training manual with a DVD of a patient demonstrating self-administration and we are enhancing our nurse training program. The combination of training the trainer and the patient will mean successful transition to SCIG for a lot more patients."

Although SCIG is not for everyone, with proper training, it is providing the mobility and freedom many patients demand to keep up with their busy lives. To determine if SCIG is appropriate for you, please contact your healthcare provider. ■

For More Information

CSL Behring's VITAL: www.cslbehring-us.com
NuFACTOR: www.nufactor.com

Case Report:

Acute stroke with high-dose intravenous immune globulin

By David A. White and Mandy C. Leonard

Purpose. A case of acute stroke in a patient who was receiving high-dose intravenous immune globulin (IVIG) for dermatomyositis is reported.

Summary. A 43-year-old woman presented with overwhelming proximal weakness and myalgias, swelling in her hands, facial and knee rash, generalized fatigue, numbness in her left arm, and lower-back pain. Physical examination revealed that she had symptoms consistent with dermatomyositis. The patient was initially treated with prednisone but developed a severe adverse drug reaction to the medication. The prednisone was discontinued, and the patient was admitted to the hospital for a first-time dose of IVIG therapy. During the infusion, the patient was found to have a facial droop, left-sided hemiplegia, and an increase in restlessness. A large, significant right internal carotid artery occlusion was discovered and initially treated mechanically and then with drugs in an attempt to establish revascularization. A subsequent computed tomography scan of the brain demonstrated a large right-middle cerebral distribution infarct with slight hemorrhage into the basal ganglia. IVIG is increasingly being used for many approved and nonapproved indications. Although rare, stroke associated with thrombosis caused by the administration of IVIG has been reported in the literature. On the basis of the Naranjo probability scale, this adverse drug event was calculated as a probable reaction due to the administration of IVIG.

Conclusion. A patient had an acute stroke after receiving a high dose of IVIG for dermatomyositis. Patients should be given a slower rate of infusion and smaller dosages of IVIG, and they should be closely monitored for potential stroke associated with thrombosis during IVIG therapy.

Index terms: Cerebrovascular accident; Dermatomyositis; Dosage; Drug administration rate; Globulin immune; Injections; Serums; Toxicity
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Intravenous immune globulin (IVIG; Gammagard S/D, Baxter Healthcare Corporation, Westlake Village, CA) is a sterile, freeze-dried preparation of highly purified immunoglobulin G derived from large pools of human plasma.¹ The process includes treatment with a solvent and a detergent that provides significant viral reduction.¹ The infusion-related adverse effects of IVIG are fatigue, headache, chills, fever, hypotension, low-back pain or chest pain, and myalgia. These adverse effects are generally self-limiting; however, serious and rare adverse reactions such as thrombotic events, aseptic meningitis, and renal dysfunction can occur.^{2,3}

IVIG is currently used as standard treatment in primary immunodeficiency diseases, B-cell chronic lymphocytic leukemia, idiopathic thrombocytopenic purpura, bone marrow transplantation, and Kawasaki disease.¹ IVIG is also used to treat a diverse group of autoimmune neuromuscular disorders that include, but are not limited to, multifocal motor neuropathy, Guillain-Barré syndrome, chronic inflammatory demyelinating polyneuropathy, myasthenia, and dermatomyositis.^{2,3} The dosage range varies widely in the literature depending on recommendations and indications; typical dosages range from 0.4 g/kg given >

as a one-time dose to 0.4 g/kg/day given over several days (2-g/kg total dose). Immunomodulatory dosing of IVIG for autoimmune indications are higher and are thought to block the Fc receptors in macrophages that prevent phagocytosis of circulating cells tagged with autoantibodies.^{4,6}

Dermatomyositis is classified as an idiopathic inflammatory myopathy.⁶ Dermatomyositis is a rare disorder in the general population with prevalence rates estimated at around 1 per 100,000 individuals. Its incidence occurs approximately twice as often in women than in men, with the peak incidence in adults occurring in the fifth decade of life. In adults, the survival rate for five years is 75%, and the majority of patients treated (up to 50%) experience long remissions and even recovery.⁷ The most common presenting feature of dermatomyositis is muscle weakness. Most patients develop an elevation of serum levels of lactate dehydrogenase, creatine kinase (CK), aldolase, alanine aminotransferase (ALT), and aspartate aminotransferase (AST). The presence of muscle weakness, myalgia, heliotrope rash (violaceous eruption of the upper eyelids accompanied by swelling), Gottron's sign (symmetric, violaceous erythematous eruption over the extensor surfaces of the joints of the fingers, elbows, and knees), and elevated serum levels of muscle enzymes increases the clinical concerns for dermatomyositis. The determining test is muscle biopsy, which establishes the diagnosis of dermatomyositis and rules out other disease states.⁶

Case Report

A 43-year-old white woman who had been previously diagnosed with idiopathic neuropathy at the age of 10 years was referred to our institution with overwhelming proximal weakness and myalgias, swelling in her hands, facial and knee rash, generalized fatigue, numbness in the left arm, and lower-back pain. The patient had not been able to drive for the past two months and could not lift her legs, turn over in bed, brush her teeth, or wash her face. A family history revealed that two of her cousins were diagnosed with a neuropathy. Several months earlier, the patient had received a diagnosis of dermatomyositis at another institution and was advised to be treated with IVIG therapy. At that time the patient refused, and she was started on oral prednisone 40 mg/day. When the daily dose of prednisone was increased to 60 mg, the patient

developed severe depression secondary to the drug, and it was tapered to 20 mg with rapid worsening of her muscular symptoms. She next began to take 10–15 homeopathic medications in conjunction with chiropractic treatments without any benefit. The patient then decided to proceed with IVIG therapy.

A physical examination on the day of the patient's admission to our clinic revealed progressive weakness, stigmata of Gottron's papules, arthralgias, and periorbital edema, all of which were suggestive of dermatomyositis. The patient's pertinent vital signs were blood pressure, 126/68 mm Hg; heart rate, 84 beats/min; body weight, 100.8 kg; and height, 66 in. She had no other comorbidities consistent with risk factors for stroke (e.g., hypertension, diabetes, previous thrombotic disease). Her selected

IVIG is currently used as standard treatment in primary immunodeficiency diseases, B-cell chronic lymphocytic leukemia, idiopathic thrombocytopenic purpura, bone marrow transplantation, and Kawasaki disease.

admission laboratory test results were thyroid-stimulating hormone, 0.131 μ units/mL (reference range, 0.4–5.5 μ units/mL); CK, 4570 units/L (reference range, 30–220 units/L); aldolase, 38 units/L (reference range, 2–8 units/L), AST, 180 units/L (reference range, 7–40 units/L); and ALT, 96 units/L (reference range, 0–45 units/L). An electromyogram showed features consistent with necrotizing myopathy, and a muscle biopsy was ordered. Several days after admission, the findings of chronic inflammation, muscle fiber degeneration and regeneration, and focal areas suggesting perifascicular atrophy were suggestive of dermatomyositis.

The patient was admitted to the general medicine service at 19:30 and was started on oral escitalopram 10 mg/day, oral esomeprazole 40 mg/day, and subcutaneous enoxaparin 40 mg/day. IVIG (Gammagard S/D) was ordered (1 g/kg/day) at 22:00 with acetaminophen 650 mg and diphenhydramine 25 mg as oral premedications. Zolpidem 5 mg was given orally at 01:15 as a one-time dose for sleep. It was documented that diphenhydramine was an allergen to the patient, and it was therefore discontinued. The IVIG infusion (100 g) was started at 02:50 and scheduled to run for four to six hours at a maximum rate of 4 mL/kg/hr. The infusion was stopped at 05:35 when the patient exhibited increasing restlessness, a left facial droop, and left-sided hemiplegia.

The neurology department was immediately consulted because it was suspected that the patient was having a stroke, and it was determined that her National Institutes of Health Stroke Scale score totaled 21, which indicated

the possibility of a stroke. A computed tomography (CT) scan demonstrated a hyperintense right-middle cerebral artery. The patient was immediately taken to angiography for potential intervention. A significant right internal carotid artery occlusion of the entire M1 segment was discovered, which was subjected to mechanical revascularization. A total of 12 mg of alteplase, 4 mg of abciximab, and 18 mg of eptifibatide were used intravenously for revascularization; however, the M1 segment remained occluded.

The patient was transferred to the neurology intensive care unit (ICU) for further evaluation and care. A transthoracic echocardiogram was performed that demonstrated no significant valvular abnormalities and an ejection fraction of 55% while her blood pressure remained within tight control. The prothrombin time and activated partial thromboplastin time values were both within the normal range. She was then started on oral aspirin 325 mg/day. A hypercoagulable panel demonstrated an elevated immunoglobulin M anticardiolipin antibody titer (i.e., a type of antiphospholipid antibody whose elevation may be indicative of an antiphospholipid syndrome). The factor VIII activity level was elevated as well, and both can be risk factors for thrombosis. It was suggested to recheck these levels in one to two months to see if there was a persistent elevation. However, for this patient, no subsequent testing was done at our institution.

While in the neurology ICU, a subsequent CT scan of the patient's brain demonstrated a large, right-middle cerebral distribution infarct with a slight hemorrhage into the basal ganglia without midline shift. The patient was discharged nine days later to our skilled nursing unit for rehabilitation. When transferred, she remained sleepy but arousable, spoke minimally, and demonstrated some dysphagia. She intermittently followed commands and grasped with her right upper extremity. The left side was hemiparetic with slight movement of the fingers on occasion. As her clinical status improved, she underwent a magnetic resonance imaging and magnetic resonance angiography of her brain, and the results demonstrated the large right-middle cerebral artery distribution infarct and a small amount of hemorrhage in the right basal ganglia. She progressed relatively well with physical and occupational therapy.

The patient was transferred 23 days later to a skilled facility closer to her home for ongoing continuation of her physical therapy. The patient's father cancelled the future

follow-up appointments with the neurologist and rheumatologist because of transportation-related reasons.

Discussion

Dermatomyositis is one of many crippling neuromuscular disorders that can deprive patients of the ability to care for themselves as well as live alone. IVIG has been used for this disorder for years and is one of the safest immunomodulating drugs available for long-term treatment, but adverse drug events can occur.² The number of complications being reported is increasing as the use of IVIG expands to new indications. Stroke caused by thrombosis is a rare and infrequent occurrence with IVIG treatment. In a case series (n = 16) by Caress and colleagues,⁸ there was a 0.6% proportion of stroke; however, the authors stated that this may be an overestimation because the patients were hospitalized and older and may have had more risk factors for stroke. The majority of events occur during or within 24 hours of the infusion, although strokes may occur at any time during the course of treatment.^{8,9}

The mechanism by which IVIG may cause stroke has not been elucidated, but several theories have been proposed. The first is a confirmed immediate increase in serum viscosity following IVIG infusion that is dependent on the dose.^{2,3,10}

Although this increase may be of no consequence in healthy patients, other patients with preexisting high-normal serum viscosity (e.g., hypercholesterolemia) or risk factors (e.g., carotid artery disease, diabetes mellitus, thrombocytosis) may be at a greater risk of developing a thromboembolic event.^{2,3,11} This increase in serum viscosity may have an accumulative effect, which may persist in certain patients, thereby explaining delayed thrombosis occurring after several doses. Other unconfirmed explanations may be the activation of platelets by IVIG, contamination of an IVIG product with coagulation factor XI, or passive infusion of antiphospholipid antibodies via IVIG infusion.^{2,3,8} In addition, therapy with IVIG may cause cerebral vascular spasm leading to ischemia and possible thrombosis, as well as have a direct effect on the vascular endothelium.^{4,9}

The role of IVIG in dermatomyositis was recently assessed in a double-blind, placebo-controlled study, in which IVIG's role was described as the interruption of complement activation products and the down regulation of several molecules as well as the modification of a number of genes. ➤

IVIG has been used for this disorder for years and is one of the safest immunomodulating drugs available for long-term treatment, but adverse drug events can occur.

Muscle biopsies showed a statistically significant increase in capillaries and muscle fiber size.¹²

There has been conflicting information on the potential risk of thrombotic events concerning the dose and rate of administration of IVIG. The Food and Drug Administration (FDA) identifies high-dose IVIG and high infusion rates in susceptible patients as possible risk factors for thrombosis, although exact parameters for the dosage and infusion rate are not specified by FDA.^{3,10} On the basis of reports in the literature, there is also the opposing opinion that strokes are not related to the infusion rate, specific product, or concentration of the IVIG solution (e.g., 5%, 10%).²

Our patient received a 5% concentrated solution of IVIG (Gammagard S/D) following the manufacturer's infusion protocol of 0.5 mL/kg/hr initially, with a maximum dosage of 4 mL/kg/hr. The exact infusion rate was not documented on the medical administration record or in the clinical notes and, therefore, could not be determined. Because of the early morning administration time, the patient was not as closely monitored, thereby eliminating the chance to closer pinpoint the time of the adverse drug event. On admission, there were not any apparent indications of a

preexisting hypercoagulable state. Application of the Naranjo adverse drug reaction probability scale indicated that, in this patient, there was a probable relationship between treatment with IVIG and stroke.¹³

Despite the rare associations of stroke and IVIG therapy that are documented in the literature, reports are increasingly surfacing with the additional use for off-label indications. Although not a confirmed cause, slower rates of administration and lower adjusted doses (0.5 g/kg/day given initially) using ideal body weight may lead to decreased adverse events. The identification of patients at risk for thrombotic events is also important. Close monitoring of patients receiving IVIG for signs of acute stroke, standard order forms and times, and nurses with specialty training in administration of IVIG should be considered.

Conclusion

A patient had an acute stroke after receiving a high dose of IVIG for dermatomyositis. Patients should be given a slower rate of infusion and smaller dosages of IVIG, and they should be closely monitored for potential stroke associated with thrombosis during IVIG therapy. ■

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High-maintenance Health

By Ever Fecske



Are we high maintenance? I mean we with immune deficiencies. Would I be accurate in saying that we "sick" people require an excessive amount of attention to maintain our health—just as the princess or diva or possessive boyfriend must be showered with gifts, always have their way and control everything around them?

Yes, we are the definition of high maintenance! And unlike the princess, diva or possessive boyfriend, for us it is actually justified. In fact, I would tell you that you must be high maintenance—for your own good health.

Being high maintenance starts with knowing what you want and not being afraid to go after it. I don't know about you, but I want the best health I can possibly have, and, if that means being demanding and assertive, then by all means call me Princess!

When you don't feel right, or there is something inside that irks you, act immediately! Don't wait around because,

if it is something, it will only get worse. And if it's nothing, you will have the peace of mind of knowing right away.

Don't be afraid to be demanding of your doctors' time. Ask the hard questions. You won't get anywhere by keeping them to yourself. Make a scene if you must. This is your life and you deserve their utmost attention. So call them, email them and be honest with them about how you feel, when and where you feel it. You don't have to be polite. Just tell them, they can take it, and the good doctors will thrive on it.

Now, if you are like me, you need a team of doctors or, as I like to refer to them, "My Entourage." We deserve the best and if that is high maintenance, then I say let's own it! Besides, I like being high maintenance. It makes me feel important in the most important way. Think about it: We have an incredibly smart, dedicated staff of people on our side, who have studied for years to be able to help us. ➤



And they help us because they want us to stick around! So humor them and let them help us. We are worth it!

Another high-maintenance indicator is spending money. Most high maintenance girls spend money on shopping for the latest trends and their looks—heaven knows, dark roots are unacceptable.

When I break it down, I figure my IVIG costs more than 10 Gucci bags a month or 22 pairs of Christian Louboutin shoes or a Volkswagen Beetle convertible. So try telling me I'm not high maintenance. And while the latest styles and accoutrements might be really glamorous and last a lot longer than the one month that IVIG stays in my body, they will eventually go out of fashion. Health, on the other hand, is never out of fashion, so I suppose IVIG is timeless, like a good strand of pearls!

They say that every girl and guy needs basic, classic staples in their wardrobe. They send a long-lasting impression that you are capable, efficient and dependable. When I think about how much effort many of us put into our wardrobes, I can't help but to compare it to the effort to maintain my high-maintenance medical situation. So, while Paris Hilton is wasting all her time at Barneys, I am taking care of the most important staple of all: my health.

I would say that my immunologist is my "little black dress." No matter the occasion, whatever the question, he, like that dress, is the answer. Dependable for various looks—sexy, sophisticated and conservative—he's knowledgeable, dependable, and, unlike my dress, he can write a prescription! I don't know what he would say if he knew I was comparing him to a piece of women's clothing, but look at it this way: Some of the most timeless women like Coco Chanel, Audrey Hepburn, and Jackie O donned the little black dress with the highest sense of fashion, just like my immunologist is my go-to guy when problems surface. I start with him and then he guides me to whoever else in my entourage needs to be involved.

Being high maintenance means accepting and acting upon the importance of what your body tells you. Whenever I feel anything, I immediately call my immunologist. When I tell my immunologist I am having pain in my stomach, sure enough I am off to the GI doc for a series of tests. High maintenance! It's too bad we never do lunch.

Between my urologist, gynecologist, hematologist, pulmonologist and an array of internists and specialists, I have a bigger entourage than P. Diddy and J. Lo combined! Not only is my entourage smart, they don't carry automatic weapons or beat up paparazzi fighting for a picture of me

in a hospital gown. I let anyone take my picture—inside and out!

There are times when I do feel somewhat famous, though. Regardless of the lab I walk into, at least two phlebotomists know me by name. If that's not fame, tell me, what is?

"Hello Ever, how are you? Where shall I stick you today? Or would you like to give me a urine sample first?" The next time he asks me this, I should say, "Ask my personal assistant!" What's next? An autograph? If only I had a "PA" to manage my hectic schedule. The photo shoots alone are enough to put Kate Moss to shame! Sure, my photo shoots are computed tomography, and require no clothing but a sheet to wrap me up like a burrito and the camera looks like the world's biggest, tasteless doughnut, but all the same, I could fill an entire issue of Vogue with my high-quality body images. Hey, Demi Moore posed naked and pregnant on the cover of Vanity Fair, so what's wrong with posing in a sheet?

It seems one of the results of my high-maintenance demands is that I am constantly on antibiotics. So I compare them to a really well-tailored, dark-washed pair of jeans. They can cure even the most frustrating, relentless infection or fashion dilemma. Dress them up with a fancy top or wear them to work with a fitted blazer. It doesn't matter what brand they are, name or generic, if you paid full price or got them off the rack, no one will know but you, and all that really matters is that they flatter, lift and clear the congestion! So my designer antibiotics are top of the line and much more essential than a pair of jeans.

Then there are all those special appearances I have to make. I think I go to the doctor's office more than Beyoncé appears on MTV. But like her, I enjoy the attention. So part of being high maintenance is not being a recluse. Go on out there and mingle! See your doctor or caregiver in person—not just on the phone. More importantly, let them see *you*.

Sometimes these special appearances turn into major red carpet events, like lung biopsies and gastric scoping explorations that take hours upon hours of preparation. The amount of time they take is pretty incredible but, remember, it's necessary if you are going to increase your celebrity status and make sure your health is getting the exposure it deserves. It's the only way for your doctors to know everything that is going on in your life. It's not enough just to read it in Variety.

So have your specialist call my specialist. And let's do lunch! 🍴

Resource Directory

Guillain-Barré Syndrome (GBS)

Websites and Chat Rooms

- The GBS/CIDP Foundation International, www.gbsfi.com, has 23,000 members in 160 chapters on five continents. 610-667-0131
- The GBS Foundation Discussion Forums provide the opportunity to talk to other GBS patients and learn more about ways to manage the illness: www.guillain-barre.com/forums.
- Miller Fisher syndrome, considered to be a variant of GBS, is explained on the National Institute of Neurological Disorders and Stroke, NINDS Miller Fisher Syndrome Information Page: www.ninds.nih.gov/disorders/miller_fisher/miller_fisher.htm.

Online Pamphlets

- The National Institute of Neurological Disorders and Stroke has a GBS Fact Sheet at www.ninds.nih.gov/disorders/gbs/detail_gbs.htm.
- The Mayo Clinic has an overview of Guillain-Barré syndrome at www.mayoclinic.com/health/guillain-barre-syndrome/DS00413.
- The National Institute of Neurological Disorders and Stroke has an information page about CIDP: www.ninds.nih.gov/disorders/cidp/cidp.htm.

Online Peer Support

- GBS & CIDP Discussion Forum – UK Bulletin Board – For Ireland and England www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi
- GBS Support Group and Chat Room, UK <http://www.jsmarcussen.com/gbs/uk/chat.htm>
- GBS Foundation Discussion Forums: www.guillain-barre.com/forums
- Yahoo Support Group Discussion Board http://health.groups.yahoo.com/group/GBS_CIDP

Books and Articles

- "A Handbook for Care Givers," by Helen Rummelsburg, gives an account of caring for her husband and offers helpful hints for patients and caregivers. Available at the GBS website bookstore at www.gbsfi.com.
- "Bed Number Ten," by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
- "Caring for a Child With GBS," by Patricia Schardt, is a short guide written by a mother of a child with CIDP. Available at the GBS website bookstore at www.gbsfi.com.
- "No Laughing Matter," by Joseph Heller (the best-selling author of Catch-22), who teamed up with Speed Vogel, his best friend, to describe Heller's battle with and triumph over GBS.

ITP (Idiopathic Thrombocytopenic Purpura)

Websites

- ITP Support Association, UK: www.itpsupport.org.uk
- Platelet Disorder Support Association: www.ITPpeople.com 87-PLATELET (877-528-3538) or 301-770-6636

Online References

- Idiopathic thrombocytopenic purpura http://en.wikipedia.org/wiki/Idiopathic_thrombocytopenic_purpura
- Idiopathic Thrombocytopenic Purpura: Michael A. Silverman, MD www.emedicine.com/EMERG/topic282.htm

- Immune Thrombocytopenia: Current Understanding and Future Research, Robert S. Mocharnuk, MD www.medscape.com/viewarticle/459249
- Infusion Network Systems article: The Expanding Use of IVIG provided by ZLB Bioplasma, Inc. www.infusionsystems.net/article-ExpandingUseofIVIG.html
- ITP: Idiopathic Thrombocytopenic Purpura: <http://familydoctor.org/113.xml>

Kawasaki Disease

Websites

- Kawasaki Disease Foundation: www.kdfoundation.org PO Box 45 • Boxford, MA 01921 Tel: 978-356-2070 • Fax: 978-356-2079 • Email: info@kdfoundation.org
- Kids Health discusses Kawasaki disease at www.kidshealth.org/parent/medical/heart/kawasaki.html.
- Overview from the American Heart Association focuses on how the disease affects the heart. www.americanheart.org/presenter.jhtml?identifier=4634

Mitochondrial Disease

Websites

- United Mitochondrial Disease Foundation promotes research and education for the diagnosis, treatment and cure of mitochondrial disorders and provides support to affected individuals and families. www.umdf.org
- The Cleveland Clinic website provides many articles when searched by the topic, "mitochondrial disease." www.clevelandclinic.org/health
- The National Institute of Neurological Disorders and Stroke provides an informative Mitochondrial Myopathies Information Page. www.ninds.nih.gov/disorders/mitochondrial_myopathy/mitochondrial_myopathy.htm

Multifocal Motor Neuropathy (MMN)

Websites

- National Institute of Neurological Disorders and Strokes (NINDS) provides a Multifocal Motor Neuropathy Information Page: www.ninds.nih.gov/disorders/multifocal_neuropathy/multifocal_neuropathy.htm
- Multifocal Motor Neuropathy Center at Johns Hopkins Department of Neurology www.neuro.jhmi.edu/MMN/index.html
- The Neuromuscular Center at Washington University in St. Louis, Mo. Neuromuscular Home Page www.neuro.wustl.edu/neuromuscular
- The Neuropathy Association is dedicated to helping those with conditions affecting peripheral nerves. www.neuropathy.org

Multiple Sclerosis (MS)

Websites and Chat Rooms

- The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS. www.nationalmssociety.org/
- All About Multiple Sclerosis provides accurate and comprehensive medical information about MS written in plain English by people living with the disease and its symptoms. www.mult-sclerosis.org/index.html

- Multiple Sclerosis Foundation works for a brighter tomorrow for those affected by MS. www.msfacts.org
- Multiple Sclerosis Association of America seeks to enrich the quality of life for individuals with multiple sclerosis. www.msaa.com
- MSWorld's Chat and Message Board features patients helping patients. www.msworld.org

Online Peer Support

- Friends with MS: <http://friendswithms.com>
Forum: <http://health.groups.yahoo.com/group/FriendsWithMS>
- My MSViews: www.mymviews.org
Forum: http://health.groups.yahoo.com/group/MSViews_Multiple_Sclerosis
- MS Support Group: <http://health.groups.yahoo.com/group/mscured>
- The MS Carousel—A Place to Meet With People Who Understand MS!
<http://health.groups.yahoo.com/group/themscarousel>

Myasthenia Gravis (MG)

Websites and Chat Rooms

- The Myasthenia Gravis Foundation of America (MGFA) is the only national volunteer health agency dedicated solely to the fight against (MG). www.myasthenia.org
- Myasthenia Gravis Fact Sheet prepared by National Institute of Neurological Disorders and Strokes. www.ninds.nih.gov/disorders/myasthenia_gravis/myasthenia_gravis.htm
- Mayo Clinic's overview of myasthenia gravis: www.mayoclinic.com/health/myasthenia-gravis/DS00375

Online Peer Support

- MGFA's Forum: <http://health.groups.yahoo.com/group/MGnet>
- Bette's Myasthenia Gravis Support: <http://health.groups.yahoo.com/group/bettesmyastheniagravisupport>
- Maddy's MG Support: <http://health.groups.yahoo.com/group/maddysmgsupport>
- Autoimmune Information Network Inc.: www.aininc.org
PO Box 4121 • Brick, NJ 08723 • 877-246-4900
Email: autoimmunehelp@aol.com

Myositis

Websites

 <p>THE MYOSITIS ASSOCIATION</p>	<p>The mission of The Myositis Association, www.myositis.org, is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. 202-887-0088</p>
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- International Myositis Assessment and Clinical Studies Group is a coalition of healthcare providers and researchers with global approaches to improved treatments and understanding of myositis: <https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main>
- The Cure JM Foundation was created specifically to find a cure for Juvenile Myositis (JM), while also providing support and information for families affected by JM. <http://curejm.com>
- Johns Hopkins Myositis Center is a new patient treatment center that brings the expertise of rheumatologists and neurologists into a single clinic for patients with inflammatory (autoimmune) and toxic (drug induced) muscle conditions. www.hopkinsmedicine.org/rheumatology/clinics/myositis_center.html

Online Peer Support

- Juvenile Myositis Family Support Network: www.curejm.com/family_support/index.htm
- Myositis Association Community Forum: www.myositis.org
- Myositis Support Group: www.myositisupportgroup.org
- Myositis Support Group UK: www.myositis.org.uk
- Yahoo Myositis Support Group Discussion Board: <http://health.groups.yahoo.com/group/OurMyositis>
- The California Myositis Symposium held in 2005 was captured on DVD. It contains information about polymyositis, dermatomyositis and inclusion body myositis, including doctors' discussions and detailed slides and explanations of muscle biopsies, skin rash, and tools used to diagnose these diseases. Other presentations offer valuable lessons in maintaining a positive attitude, exercises for physical therapy and innovative tools to aid in everyday activities. The DVD is available at no charge by sending an email to Richard Gay at rgay@socal.rr.com.

Books and Articles

- "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.
- "Inclusion-Body Myositis and Myopathies," by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.
- "Living With Myositis," edited by Jenny Fenton, is an accessible, realistic and sympathetic guide to facts, feelings and future hopes.
- "Myositis—A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References," by ICON Health Publications, is a three-in-one reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.
- "Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers" is an indispensable resource for families of children with myositis and their healthcare teams is available at www.myositis.org.
- "The Official Patient's Sourcebook on Inclusion Body Myositis," by James N. Parker (Editor) and Philip M. Parker (Editor), is a reference manual for self-directed patient research.

Pemphigus and Pemphigoid

Websites

- The International Pemphigus and Pemphigoid Foundation provides information and support to people living with the autoimmune diseases. www.pemphigus.org
- Information from the National Institutes of Health: www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm
www.nlm.nih.gov/medlineplus/ency/article/000882.htm
- Rare disease report: <http://rarediseases.about.com/od/rarediseasesp/a/pemphigus05.htm>

Peripheral Neuropathy (PN)

Websites

 <p>The Neuropathy Association</p>	<p>The Neuropathy Association, www.neuropathy.org, is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association's mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, advocate the need for early intervention and support research into the causes and treatment of neuropathies. 212-692-0662</p>
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- To learn about PN, how it is classified, the symptoms, causes and treatments, see the Peripheral Neuropathy Fact Sheet available at www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm.
- The Neuropathy Action Foundation, at www.neuropathyaction.org, educates, empowers and informs patients and physicians about neuropathy.

Support Groups

- Click on the Member Services tab of the website, www.neuropathy.org, for listings of support groups across the nation.

Online Peer Support

- Calgary Neuropathy Support Group: www.calgarypnrs.org/index.htm
- MSN Support Group Discussion Board: <http://groups.msn.com/PNPARTNERS>
- The Neuropathy Association Bulletin Board: www.neuropathy.org
- Yahoo Neuropathy Support Group Discussion Board: <http://health.groups.yahoo.com/group/neuropathy>
- Yahoo Support Group – Australia Discussion Board: <http://au.groups.yahoo.com/group/LifeWithPN>

Books and Articles

- “If You’re Having a Crummy Day, Brush Off the Crumbs!,” by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.
- “Medifocus Guide to Peripheral Neuropathy,” is a guide to current and relevant PN research, organized into categories for easy reading.
- “Numb Toes and Aching Soles,” by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
- “Numb Toes and Other Woes,” by John Senneff, is the second in a series of three books. It focuses on clinical findings and treatment strategies for PN.
- “Nutrients for Neuropathy,” by John Senneff, the third in the Numb Toes series, is focused exclusively on nutrient supplementation as a means for managing PN.
- “Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won’t Stop” by Dr. Norman Latov, MD, PhD, published 2007, Weill Medical College, Cornell University, provides practical information on all the neuropathies, causes and treatments.

Primary Immune Deficiency Disease (PIDD)

Websites and Chat Rooms

 <p>IMMUNE DEFICIENCY FOUNDATION</p>	<p>The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is dedicated to improving the diagnosis and treatment of PIDD through research and education. 800-296-4433</p>
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	<p>The Jeffrey Modell Foundation, www.info4pi.org, is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency. 212-819-0200</p>
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- The National Institute of Child Health and Human Development (NICHD), www.nichd.nih.gov, is part of the National Institutes of Health. Go to the “Health Information and Media” tab on the website and do a search under “primary immunodeficiency.”
- The American Academy of Allergy, Asthma & Immunology, www.aaaai.org, has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.

- The Michigan Immunodeficiency Foundation, www.midf.org, seeks to improve the quality of life for Michigan residents affected by PIDD.
- The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PIDD patients.
- To connect to a PIDD message board, go to www.info4pi.org.
- To chat with peers on IDF’s Forum, go to www.primaryimmune.org/forums/forum_intro.htm.
- Chat with parents of children affected by primary immune deficiency at <http://health.groups.yahoo.com/group/PedPID>.
- Chat with peers with PIDD at <http://health.groups.yahoo.com/group/PIDsupport>.
- A group of family and friends of patients with primary immune deficiencies maintains a nonprofit network in the New England area: www.nepin.org
- Baxter’s website, www.immunedisease.com, offers in-depth information on immunology, PIDD and treatment with intravenous immune globulin. Click on “European” to see SCIG information.

Online Pamphlets and Education

- Go to the National Institute of Allergy and Infectious Diseases site at www.niaid.nih.gov and search for “primary immune deficiency.”
- “Understanding the Immune System: How It Works,” by the U.S. Department of Health and Human Services, is found at www.niaid.nih.gov/publications/immune/the_immune_system.pdf
- “NIAID Initiative Addresses Primary Immune Deficiency Diseases by National Institute of Allergy and Infectious Diseases” is located at <http://www3.niaid.nih.gov/news/newsreleases/2003/pirc.htm>
- The “Immunodeficiency in Pediatrics” program (PREP®) Audio series is a new pediatrician education program that can be obtained by contacting the American Academy of Pediatrics at 866-843-2271 or visiting www.prepaudio.org.

Online Peer Support

- Chat with parents of children affected by PIDD <http://health.groups.yahoo.com/group/PedPID/>
- Chat with peers with PIDD: <http://health.groups.yahoo.com/group/PIDsupport/>
- Immune Deficiency Foundation Forum www.primaryimmune.org/forums/forum_intro.htm
- Jeffrey Modell Foundation Message Board: www.info4pi.org

Books and Articles

- “21st Century Complete Medical Guide to Primary Immune Deficiency, Severe Combined Immunodeficiency (SCID), Chronic Granulomatous Disease (CGD), for Patients and Physicians,” by PM Medical Health News, contains federal government clinical data and practical information for patients and physicians.

Scleroderma

Websites

- Johns Hopkins Medicine Scleroderma Center: scleroderma.jhmi.edu
- Scleroderma Research Foundation: www.srfcure.org
- Scleroderma Foundation: www.scleroderma.org

Online Peer Support

- Educating instead of medicating CureZone.com <http://curezone.com/forums/f.asp?f=404>
- International Scleroderma Network www.sclero.org/support/forums/a-to-z.html

Stiff-Person Syndrome (SPS)

Websites

- American Autoimmune Related Diseases Association Inc., www.aarda.org, is the only national organization dedicated to addressing the problem of autoimmunity. 800-598-4668 aarda@aarda.org
- Autoimmune Information Network Inc., www.aininc.org, helps patients and family cope with the disabling effects of autoimmune diseases. 732-262-0450 autoimmunehelp@aol.com
- National Association for Rare Disorders (NORD), www.rarediseases.org, promote awareness of rare diseases and the need for research. 800-999-6673 orphan@rarediseases.org
- National Institute of Neurological Disorders and Stroke (NINDS), www.ninds.nih.gov, offers treatment, diagnosis and research information for rare diseases. 800-352-9424 braininfo@ninds.nih.gov
- Diagnosed with SPS in 1994, Debra Kemery recounts her experience and offers practical information about coping with the disease at www.stiffman.org.

General Resources

Product Information

- Influenza and the influenza vaccine www.cdc.gov/flu or call 800-CDC-INFO (800-232-4636)
- IVIG Carimune NF www.carimune.com
- IVIG Flebogamma www.grifolsusa.com/flebogamma.htm
- IVIG Gammagard Liquid www.gammagardliquid.com
- IVIG Gammagard S/D www.immunedisease.com/US/therapies/gammagard/index.html
- IVIG Gamunex www.gamunex.com
- IVIG Octagam www.octapharma.com/corporate/03_products_and_therapeutic_areas/01_immunoglobulin_product_line/03_octagam.php
- SCIG (subcutaneous immune globulin) Vivaglobin www.vivaglobin.com

Other Organizations

- Alliance for Plasma Therapies is a unified, powerful voice of patient organizations, healthcare providers and industry to advocate for fair access to plasma therapies. www.plasmaalliance.org
- For suggestions on how to deal with the medical and emotional impact of caring for an ill child, go to www.kidshealth.org/parent/system/ill/seriously_ill.html.
- The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at www.ncqa.org.
- The nonprofit Patient Advocate Foundation, www.patientadvocate.org, seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274



The nonprofit Patient Services Incorporated, www.unneedpsi.org, specializes in health insurance premium, pharmacy co-payment and co-payment waiver assistance for people with chronic illnesses. 800-366-7741

- WebMD, www.webmd.com, is a handy medical reference that helps consumers take an active role in managing their health by providing objective healthcare and lifestyle information.

- For a pediatrician's guide to your child's health and safety, visit www.keepkidshealthy.com.
- The National Organization for Rare Diseases, at www.rarediseases.org, provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.
- American Autoimmune Related Diseases Association (AARDA) www.aarda.org brings national focus to autoimmunity through research, education and patient services. 800-598-4668
- Band-Aides and Blackboards, www.lehman.cuny.edu/faculty/jfleitas/bandaides, started by a nurse working on her dissertation, focuses on children with chronic illness.
- American Chronic Pain Association (ACPA) was founded in 1980 to provide resources for people coping with chronic pain. www.theacpa.org

Education and Disability Resources

- Continuation of Health Coverage—Consolidated Omnibus Budget Reconciliation Act (COBRA): www.dol.gov/dol/topic/health-plans/cobra.htm
- Social Security: www.ssa.gov/disability
- California State Disability Insurance (SDI): www.edd.ca.gov (Please note that each state has a different disability program.)
- IDEA 2004 Resources: www.ed.gov/policy/speced/guid/idea/idea2004.html News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities.
- The National Disabilities Rights Network: www.ndrn.org. This website offers a search tool to find resources in your state to assist with school rights and advocacy.
- U.S. Department of Education Website: www.ed.gov. This website, a U.S. federal government website, offers a parents section that has a subsection titled "My Child's Special Needs" that can be most helpful.
- U.S. Department of Health and Human Services, Office of Civil Rights, www.hhs.gov/ocr/504.html, spells out your rights under Section 504 of the Rehabilitation Act.
- Wrightslaw: www.wrightslaw.com. Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities.
- The Americans with Disabilities Act of 1990 Provides protection for people with disabilities from certain types of discrimination and requires employers to provide some accommodations of the disability. For more information, visit www.usdoj.gov/crt/ada/adahom1.htm.

Additional Reading

- "Anatomy of an Illness," by Norman Cousins, is a best-seller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body's capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
- "A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed," by Linda Wilmshurst and Alan W. Brue, is available on Amazon.com.
- "The Confused Consumer's Guide to Choosing a Health Care Plan: Everything You Need to Know," by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.
- "The Everyday Guide to Special Education Law," by Randy Chapman, Esq., makes the law accessible to parents so they can be more effective advocates for their children. Available at www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15.

- "Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration," by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.
- "Managing Pain Before It Manages You," by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.
- "Not Dead Yet: A Long Strange Trip From Doctor to Patient and Back Again," by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.
- "Pride and the Daily Marathon," by Jonathan Cole, describes how Ian Waterman was suddenly struck down at work by a rare neurological illness that deprived him of all sensation below the neck, and how he reclaimed a life of full mobility.
- "Pronoia Is the Antidote for Paranoia," by Rob Breznsy, explores the best way to attract the blessings that the world is conspiring to give us.
- "When You're Ill or Incapacitated" comprises one-half the booklet it shares with "When You're the Caregiver," both written by James E. Miller, suggesting 12 things to remember or do in each role.
- "YOU the Smart Patient: An Insider's Handbook for Getting the Best Treatment," by Michael F. Roizen, MD, and Mehmet C. Oz, MD, with the Joint Commission on Accreditation of Healthcare Organizations, shows you how to tackle such healthcare decisions as picking the best doctors and hospitals for you, knowing when to get a second opinion, and more.

IG Manufacturer Websites

- Baxter: www.baxter.com
- Octapharma: www.octapharma.com
- CSL Behring: www.cslbehring.com
- Talecris: www.talecris.com
- Grifols: www.grifolsusa.com

Pump and Infusion Sets Websites

- EMED Corporation: www.safetymedicalproducts.com
- Graseby Marcal Medical: www.marcalmedical.com
- Intra Pump Infusion Systems: www.intrapump.com
- Repro Med Systems, Inc: www.repro-med.com
- Norfolk Medical: www.norfolkmedical.com

Medical Research Studies

- Check out the official website for the National Institutes of Health patient recruitment program. This site provides summaries and criteria for studies as well as the ability to search for studies being conducted for a specific disease or disorder. <http://clinicalstudies.info.nih.gov>
- This website provides a wealth of information about clinical trials and volunteer participation. It gives you the ability to specify the disorder you are interested in, the location of the study, and the medication names or research protocols. www.centerwatch.com
- This site has a registration form to request that you be notified about recruitment for future studies. www.clinicaltrials.com
- WebMD has a service that matches volunteers with trials. There is an online questionnaire to complete and you will be notified via email of upcoming studies that match the criteria of your questionnaire. You can also search for specific studies. www.webmd.com

Food Allergies

- Allergic Disorders: Promoting Best Practice www.theallergyreport.com/reportindex.html
- American Partnership for Eosinophilic Disorders: www.apfed.org
- National Institutes of Health, National Institute of Allergy and Infectious

Diseases (2004). Food Allergy: An Overview (NIH Publication No. 04-5518). www.niaid.nih.gov/publications/pdf/foodallergy.pdf

- Food Allergy and Anaphylaxis Network: 800-929-4040 www.foodallergy.org
- World Allergy Organization: www.worldallergy.org
- Sicherer, S.H. (2006). "The Complete Peanut Allergy Handbook: Understanding and Managing Your Child's Food Allergies," Johns Hopkins Press.

Nutrition and Food Safety

- American Board of Physician Nutrition Specialists: www.ipnec.org
- American Dietetic Association: www.eatright.org
- American Gastroenterological Association: www.gastro.org
- North American Society for Pediatric Gastroenterology Hepatology and Nutrition: www.naspgn.org/
- Bovine spongiform encephalopathy (BSE) www.aphis.usda.gov/newsroom/hot_issues/bse.shtml
- Childhood choking prevention: www.ific.org/publications/brochures/index.cfm
- American Academy of Allergy, Asthma & Immunology (AAAAI): www.aaaai.org Patient Information and Physician Referral Line: 800-822-2762
- The Food Allergy & Anaphylaxis Network: www.foodallergy.org 800-929-4040
- U. S. Food and Drug Administration, Center for Food Safety and Applied Nutrition www.cfsan.fda.gov Food Information Line (24 hours): 888-SAFEFOOD
- USDA Meat and Poultry Hotline: www.IsItDoneYet.gov 888-MPHotline 888-674-6854 · TTY: 800-256-7072
- Dietary Guidelines for Americans, 2005 Edition: www.health.gov/dietaryguidelines
- Drug Nutrient Interactions (MedlinePlus & the Physician Desk Reference): www.nlm.nih.gov/medlineplus/ or <http://www.pdrhealth.com>
- Electronic menu planner: <http://hp2010.nhlbi.nih.gov/menuplanner/menu.cgi>
- Modified Food Pyramid for Older Adults (Tufts): <http://nutrition.tufts.edu/consumer/pyramid.html>
- The American Dietetic Association or to find a registered dietitian in your area: www.eatright.org or 800-877-1600
- USDA: MyPyramid personal nutrition tracker: www.mypyramid.gov

Reading Just for Kids

- "Germs Make Me Sick," by Melvin Berger, explains with colorful illustrations how your body fights germs.
- "Little Tree: A Story for Children With Serious Medical Illness," by Joyce C. Mills, is a comforting fable for young children facing serious life challenges.
- "My IVIG Book," written from a 3-year-old's perspective about his infusions, comes with a kit for other children to create their own personalized book. Free from Baxter at www.immunedisease.com/US.
- "Our Immune System," enables children who are immune deficient and their families to explore together the immune system. Available from the Immune Deficiency Foundation at www.primaryimmune.org.

Have something to add to these pages? Please send your suggestions for additions to the IG Living Resource Directory to editor@igliving.com. In this case, more is indeed better!

When it comes to flu vaccine,
timing is everything!



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