Ensuring Infusion Nurses Are Properly Trained

A Roadmap for Decoding Medical Bills

Managing Care During Limited Access

Goal-Setting Guidance for Chronic Illness

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WHEN LIVING with a chronic illness, the central burden is how to manage the condition. So where do patients start? Some dominant concerns come to the forefront, including accessing treatment, ensuring proper care, interpreting medical bills, reprioritizing everyday goals and getting needed support. Our intent with this issue is to provide guidance in each of these areas.

According to the U.S. Food and Drug Administration, immune globulin (IG) is a “medically necessary” medicine since it is used to treat or prevent serious diseases or medical conditions for which no acceptable drug alternative is available. Without access to IG, many patients risk chronic debilitation, permanent physical damage and even death. Currently, for only the second time in history, IG is in short supply with no clear indication of when the shortage will resolve. To help patients access this lifesaving medicine, Rachel Colletta, director of educational resources at the Immunoglobulin National Society, explains in her article “Managing Care During Immune Globulin Product Shortages” (p.20) the causes of these shortages and the options patients can consider such as product choice, site of care and insurance.

Equally important as access to therapy are patient outcomes with IG infusions, which often depend on infusion nurses’ proficiency. As we discuss in our article “The Importance of Properly Trained Infusion Nurses” (p.24), this specialized field requires knowledge about the diseases treated with IG, routes of administration, side effects/adverse events and how to mitigate them. Patients will benefit from understanding the basic educational requirements for infusion nurses to ensure they receive excellent quality care.

Considering the high costs of IG therapy, patients must also protect their financial health. In our article “A Guide to Decoding Medical Bills” (p.28), we list the financial forms patients should become familiar with and what each entails, the billing process required by insurance companies and what information patients should look for on these forms to ensure they are only paying what they owe.

Finally, patients must consider the activities and relationships affecting their physical and mental health. Our article “Setting Goals and Managing Expectations for Chronic Illness” (p.32) provides guidance on setting specific, measurable, attainable, realistic and time-based goals, as well as how to keep expectations balanced. And, our article “Finding Support with Chronic Illness” (p.36) highlights the sources of support available to help patients deal with their condition and explore how life can be enriched even while living with an illness.

As always, we hope you enjoy these articles, as well as the many more educational and insightful topics presented in this issue of IG Living.
In recent years, healthcare in the United States has become a political hot potato with both sides unable to agree on much, particularly when it comes to insurance. In this arena, surprise medical bills have caught the attention of both sides of the political aisle noting their unfair impact on patients.

Surprise medical bill is a term used to describe unexpected charges arising when an insured individual inadvertently receives care from an out-of-network provider. Most of these bills result when health insurers don’t pay the provider’s full charges and patients are billed the difference. The surprise medical bill can occur in many situations, but the two most common are when emergency medical services are provided by an out-of-network provider or when emergency or nonemergency medical services are rendered by an out-of-network provider in an in-network facility.

While a surprise medical bill is never welcome, the reasons for them are particularly unfair to patients. In the first instance, when a patient goes to an emergency room (ER), it is usually for a serious, unexpected or life-threatening condition. This means the individual has little or no ability to select an ambulance service, hospital or treating physician in network. On average, 18 percent of ER visits leave patients with at least one out-of-network charge. The majority of these charges come from doctors who work at the treating facility but are considered out of network. If the patient is admitted to the hospital from the ER, the likelihood of receiving an unexpected bill jumps a staggering 26 percent.

Surprise medical debt disproportionately contributes to medical debt for insured patients. One-third of insured, nonelderly people struggle to pay medical debt related to surprise billing. So, what can be done to help protect patients from the financial hardship that unexpected bills can bring?

Several states have proposed pending legislation, and both New York and California have laws in place concerning the issue. Unfortunately, that is not enough. State protections don’t apply to most large-employer plans that fall under federal regulations, which leaves many exposed to potential medical debt. To close this gap in the law, legislation is needed at the federal level.

Currently, several legislative solutions are being discussed in both the House and Senate with bipartisan support. These include hold-harmless provisions that protect consumers from the added cost of surprise medical bills, including limits or prohibitions on balance billing. Other measures include disclosure requirements that call for health plans and/or providers to notify patients in advance that surprise balance billing may occur, potentially giving them an opportunity to choose other providers.

As policymakers search for an equitable solution, input is needed from consumers. It is important to remember that receiving care from an out-of-network provider can happen through no fault of one’s own, and potentially affects everyone. Individuals are encouraged to contact their representatives and urge passage of legislation that protects patients under these circumstances. Senators can be located at www.senate.gov/general/contact_information/senators_cfm.cfm. Representatives in the House can be located at www.house.gov/representatives.

Abbie Cornett is the patient advocate for IG Living magazine. She can be reached at patient advocate@igliving.com or (800) 843-7477 x1366.

**References**

Sadly, I have, just like many others. Only another patient fighting a rare disease can truly understand the bias we experience from time to time because of our disease. Sometimes I have to remind myself I am not in this fight alone.

— Jenny G

So many doctors are dismissive, and some seem insulted when I [suggest] their actions need to reflect my illness, not the common action. I once asked a specialist if he had any other common variable immune deficiency patients, and he haughtily answered: “Of course, it’s not that rare.” And, he was a bit huffy toward me moving forward. Only one of my many specialists has ever asked any questions about my illness and treatment. I’ve had doctors dismiss and minimize it. It’s stressful to have to go to a doctor. I don’t know if I’ll get someone on my team or resistance.

— Vicki DH

When I’m feeling good, I try to go to the warm water therapy pool three times a week, but I have other health issues that happen, [so] sometimes it’s a couple weeks [when] I don’t do anything. It’s not easy. It feels like every time I take three steps forward, it’s five steps back. Years ago, I taught aerobics and was a personal trainer, bodybuilder and runner. Not anymore.

— Donna G

Funny, [since] I took my magazine with me today to read while waiting at my physical therapy place. Talk about timely articles! As much as I don’t feel up to it, sometimes I do find it does actually feel better to move, at least a little every day!

— Jenny G

I think technology has changed some things for the better, especially the ability for the patient to use the patient portal 24/7. Using the patient portal helps streamline some communications between doctors and patients, instead of information going through multiple channels before being delivered. If I choose to contact my physician, my information goes directly to the intended party in my own words, [so something isn’t lost] by relaying information through a call center, then the nurse/medical assistant [and] then finally to the physician. I can ask questions and share information at any time I choose. However, technology also can slow things down in a variety ways, especially if the technology between physicians doesn’t communicate [properly], things don’t get scanned or get scanned in to the wrong areas, etc.

— Susan ES
Abbie » I spoke with Terry O. Harville, MD, PhD, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, who explained there are several issues at work. First, in certain circumstances, the failing immune system retains parts of immunity that would normally be eliminated, since these could cause autoimmunity such as cytopenias. He compared this process to “letting prisoners out of jail to act as soldiers! It probably wouldn’t work well.” The failing immunity may be trying to do the best it can to fight infections, even at risk for autoimmunity.

Second, we now know there are approximately 400 gene mutations that can cause immunodeficiency, autoimmunity or both in the same person. Therefore, in some circumstances, cytopenias appear first, then the immunodeficiency or vice versa. Or, both may be discovered simultaneously. So, having cytopenias in addition to an immunodeficiency is not considered rare.

Following is a list of some of the gene mutations that can cause autoimmunity, immunodeficiency or both. Note there are several listed that can cause hematologic issues (cytopenias):

<table>
<thead>
<tr>
<th>Gene Affected</th>
<th>Primary Immunodeficiency</th>
<th>Autoimmunity</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIRE</td>
<td>APECED</td>
<td>Polyendocrinopathy</td>
</tr>
<tr>
<td>BAFF-R</td>
<td>Common Variable Immunodeficiency</td>
<td>Hematologic, Other</td>
</tr>
<tr>
<td>BCL10</td>
<td>Antibody Deficiency</td>
<td>Gastrointestinal Disease</td>
</tr>
<tr>
<td>CD19</td>
<td>Common Variable Immunodeficiency</td>
<td>Hematologic, Glomerulonephritis, Other</td>
</tr>
<tr>
<td>CD81</td>
<td>Antibody Deficiency</td>
<td>Glomerulonephritis, Other</td>
</tr>
<tr>
<td>CTLA4</td>
<td>Antibody Deficiency</td>
<td>Lymphoproliferation, Other</td>
</tr>
<tr>
<td>FOXP3</td>
<td>IPEX</td>
<td>Immunodysregulation, Polyendocrinopathy and Enteropathy, X-linked</td>
</tr>
<tr>
<td>ICOS</td>
<td>Common Variable Immunodeficiency</td>
<td>Hematologic, Other</td>
</tr>
<tr>
<td>IL21</td>
<td>Antibody Deficiency</td>
<td>Colitis, Other</td>
</tr>
<tr>
<td>LRBA</td>
<td>Antibody Deficiency (IgG and IgA)</td>
<td>Inflammatory Bowel Disease</td>
</tr>
<tr>
<td>MSH-5</td>
<td>Common Variable Immunodeficiency</td>
<td>Hematologic, Other</td>
</tr>
<tr>
<td>NFKB2</td>
<td>Antibody Deficiency</td>
<td>Alopecia, Endocrine Adrenal</td>
</tr>
<tr>
<td>PIK3CD (p110)</td>
<td>Antibody Deficiency</td>
<td>Lymphoproliferation, Inflammatory Bowel Disease</td>
</tr>
<tr>
<td>TNFRSF5</td>
<td>Decreased IgG, IgA (IgM normal or increased)</td>
<td>Gastrointestinal Disease</td>
</tr>
<tr>
<td>TNFRSF7</td>
<td>Antibody Deficiency</td>
<td>Aplastic Anemia</td>
</tr>
<tr>
<td>TNFSF12</td>
<td>Decreased IgA and IgM</td>
<td>Glomerulonephritis, Other</td>
</tr>
</tbody>
</table>

For more information, go to primaryimmune.org/about-primary-immunodeficiencies/relevant-info/autoimmunity.

» Have a question? Email us at editor@IGLiving.com.
Your information will remain confidential unless permission is given.

ABBIE CORNETT is the patient advocate for IG Living magazine.
IN THE PREVIOUS issue, we discussed the system of classification of histopathologic reactions. While this system was somewhat helpful, it also adds confusion due to the interchangeable language used between “hypersensitivity reactions” and “allergic reactions.” For instance, types I, II, and III hypersensitivity reactions were known to involve antibodies, but IgE, which is associated with the type I reaction, was not discovered until three years later.1 There had long been a suspected “reaginic” antibody associated specifically with allergic disease manifestations, and the discovery of IgE in 1966 confirmed this suspicion. (Reaginic was a term used to define a substance or protein that interacted with mast cells and caused those cells to release allergic mediators such as histamine.) Type I hypersensitivity has subsequently been defined as the allergic reaction associated with IgE, which is what people typically think of as allergies.

Contrary to what many may imagine, IgE was not produced during evolution just to plague individuals with hay fever and risk of anaphylaxis (severe allergic reaction). Rather, it evolved to protect us from parasites. During evolution, while the immune system was co-evolving within organisms, several issues were addressed to allow for successful reproduction of a species. One very important issue was to maintain a pregnancy. The mother’s body should not fight off or reject the baby, mistaking it for a cancer or an infection (after all, one half of the baby’s genome is from the father, and since that is different from the mother’s genome, the immune system would be expected to activate in opposition to it). In addition, the baby’s developing immune system needs to be tempered to not reject the mother’s noninherited components. Therefore, a state of tolerization is needed. This occurs when the mother’s and baby’s immune systems establish what is known as a “Th2” state, which ensues when the immune system components responsible for tolerization come to the forefront of activity.

Moreover, and equally as relevant, Th2 immunity is in part designed to fight parasites. Therefore, during pregnancy, the mother will be immunologically tolerant of the baby, less likely to become infected with parasites and better able to fight parasites that may be present. Obviously, infections with parasites would deprive the mother of the extra energy from food sources she needs for a successful pregnancy (remember, all this was occurring during evolution — well before food was cleaned, prepared or cooked). Further, after birth, the baby would be better protected from parasites and, consequently, provided a better chance to grow and develop.

The Th2 immune state is one in which Th2-type T lymphocytes activate B lymphocytes for production of antibodies, including IgE. Mast cells are found along the gastrointestinal respiratory tracts near the surfaces that can be exposed to the outside world and come into contact with parasites. Mast cells secrete compounds that are very irritating such as histamine. They have specific receptors on their cell surfaces that bind IgE (FcE). If the IgE can recognize and bind to a parasite, for example in the GI tract, the mast cell is triggered to release chemical mediators, which are very irritating to the parasite, causing it to want to leave (Figure). Unfortunately, in the modern world, things such as pollen grains are mistaken for parasitic attack, and allergic disease is the result.

We will continue with the topic of IgE-mediated type I hypersensitivity and allergic disease in the next issue.  

TERRY O. HARVILLE, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences and a consultant for immunodeficiencies, autoimmunities and transplantation.

Reference

AS SOMEONE with a chronic illness, I know life can be extremely hard and unpredictable. Chronic illness causes pain that is both physical and emotional. To deal with this pain, many of us go to great lengths to distract ourselves by going “numb” or criticizing and judging ourselves. Unfortunately, in addition to struggling with pain, weakness or other symptoms, we wind up berating ourselves or using the little energy we have to try to escape the pain. But, another option most of us rarely consider is self-compassion.

Let’s say you are feeling particularly weak and ill one day, and you confide in two friends. One friend says, “Just think positive!” or “It’s all in your head!” or “Are you sure you’re too sick to go out? You weren’t sick yesterday.” The other friend says, “I can imagine you might be really disappointed and frustrated about that. I’ve got your back. Whatever you need, I’m here for you.” Which friend is being more helpful? Most of us would say the second friend, right? That friend is engaging in compassion. So, why not offer yourself that same compassion?

Think about what you do and say to yourself when you feel ill or are in pain. Do you blame yourself, deny your feelings or let them consume you? Instead of doing those things, what if you treated yourself with support and kindness like the second friend did? For instance, you could do things for yourself that are caring, or say things to yourself that are kind. You could pray or meditate or engage in myriad activities to treat yourself compassionately.

Some of us worry that, if we are too gentle with ourselves, we will lose the motivation to keep going when we feel ill or are in pain. In response to that concern, let me provide another analogy: Consider a working animal on a farm. You can motivate the animal with a carrot or punish the animal with a stick. The stick will work to motivate the animal, but the animal will also become miserable. On the other hand, the carrot will motivate the animal and leave the animal happy and healthy. Do you try to motivate yourself with carrots or sticks?*

Following are some ways you can treat yourself with more compassion:

• Acknowledge the pain instead of numbing yourself or trying to escape from it.
• Recognize that painful thoughts and feelings are part of being human. Everyone experiences pain and struggles in one way or another. Painful thoughts and feelings are not a sign of weakness.
• Practice speaking to yourself with kindness.
• Allow the pain to be present without trying to fight it or deny it. Simply let it be there, and turn your attention and energy toward things that really matter to you: family, friends, work, connecting with others — whatever you truly value.

Treating yourself with compassion is a courageous act. It takes practice and is harder than avoiding it. It does not make the illness or pain go away. However, learning to allow it to be present and to respond with kindness will free up your time, energy and attention to focus on things that matter and that you enjoy.

For more information on self-compassion and to find specific exercises, go to self-compassion.org or read the book The Mindful Self-Compassion Workbook: A Proven Way to Accept Yourself, Build Inner Strength, and Thrive by Kristin Neff and Christopher Germer.

ERIKA LAWRENCE, PhD, LCP, is director of translational science at The Family Institute at Northwestern University, Evanston, Ill.

*This metaphor was adapted from ACT Made Simple, 2nd Edition (2019) by Russ Harris.

Author’s note: The writer of this column does not benefit financially or in any way by recommending the book above.
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**The Role of IgG in the Human Body**

By Michelle Greer, RN, and Marc Goldstein, MD

**IMMUNE GLOBULINS (IGs)** are a vital part of the immune system. There are five types of IGs in the human body — IgG, IgM, IgA, IgD and IgE — each of which has a specific function to protect the body against foreign invaders. IgG is the most prevalent IG in blood plasma, and it is found in the blood and bodily fluids to protect extracellular tissue from viruses, bacteria and fungi. It is the only IG that crosses the placenta and protects a newborn in the first few months of life. Normal total serum IgG levels start at around 500 at birth, decrease after approximately one month and then gradually increase until about age 10 years, where they remain at that level until adulthood and then mildly decrease.

**IgG Subclasses**

There are four IgG subclasses: IgG1, IgG2, IgG3 and IgG4. Each of these differ from one another in their initial amino acid sequence, physical and chemical properties and different age-dependent serum concentrations. Just as IgG levels change with age, so do IgG subclass levels.

IGs are also known as antibodies, and antigens are foreign invaders (things that enter the body that shouldn’t be there). Antibodies and antigens are molecules that come in different forms and are generally proteins, peptides/amino acids or polysaccharides/sugars. When an antigen enters the body, an antibody will attach to it to mark it for destruction. In most cases, there is one antibody produced for every type of antigen.

IgG subclasses play a specific role in the immune response to different types of antigens. And, their levels will vary, with IgG1 being the most prevalent and decreasing in order of abundance. IgG subclasses differ in function as well: IgG1 compromises about 60 percent to 65 percent of total IgG, and provides immune response against protein and peptide antigens; IgG2 comprises about 20 percent of total IgG, and provides immune response to polysaccharide antigens; IgG3 comprises about 10 percent of total IgG, and plays a major role in immune responses to protein and peptide antigens; and IgG4 comprises about 4 percent or less of total IgG, but its role is not well-defined.

When total serum IgG is low, it is known as hypogammaglobulinemia. There are many causes of hypogamma-globulinemia, so a low IgG in and of itself requires further testing and evaluation. The other immune globulins (IgM, IgA, IgE and IgD), as well as IgG subclasses, would be part of this immunologic evaluation. It is also possible to have a normal total IgG and have low subclasses, which is known as IgG subclass deficiency. Typically, if IgG1 is low, the total IgG will be low, but if just the other subclasses are low, the total IgG can still be within normal range.

**IgG Subclass Deficiency Treatment**

IgG subclass deficiency does not necessarily require treatment with IG replacement therapy. Clinically sig-
Significant IgG subclass deficiency that requires IG replacement therapy occurs when there is both a reduction in IgG subclass(es) with normal total serum IgG, as well as evidence of antibody dysfunction with a history of recurrent infections and evidence of poor IgG antibody response to vaccines. Therefore, when total serum IgG or IgG subclasses are low, it is essential to evaluate the immune system’s ability to mount a response to a vaccination. And, because different antigens come in different forms as noted previously, vaccination can be in those forms as well: protein, peptide or polysaccharide. This provides a better evaluation of the effectiveness of the various IGs and IgG subclasses.

When individuals are deficient in one or more IgG subclasses, they typically present with recurrent upper respiratory infections with one or more episodes of pneumonia and/or bronchitis due to a bacteria or virus. In children, infections might be in the ear or sinuses.

If the individual has a progressing primary immunodeficiency. At this point, IG replacement therapy may or may not be initiated. This is particularly true for children with IgG subclass deficiencies because they can outgrow them since IgG levels change with age. And, sometimes someone can start on IG replacement therapy and then no longer need it. Alternatively, someone can initially not need IG replacement therapy, but later at some point require it.

Ongoing Monitoring Is Required
All in all, a deficiency in one or more IgG subclasses requires a thorough workup, ongoing evaluation of immune function and alterations in the treatment plan as needed.

MICHELLE GREER, RN, is senior vice president of sales for Nufactor, a Specialty Infusion Company. MARC GOLDSTEIN, MD, is chief of allergy and immunology at Pennsylvania Hospital at the University of Pennsylvania and associate professor of clinical medicine at Drexel University College of Medicine.

**Reference**

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**IgG Subclasses**
- IgG1: Most common IgG (60 percent to 70 percent) that provides protection against diphtheria, tetanus, viruses
- IgG2: Polysaccharide antigens providing protection against hemophilus, pneumococcus
- IgG3: Antibodies to proteins providing protection against diphtheria, tetanus, viruses
- IgG4: Role not well-defined
- Natural history: IgG subclass deficiency associated with recurrent ear, sinus and lung infections that usually resolves by adulthood
- Treatment: Prophylactic antibiotics and immune globulin

**Symptoms of IgG Deficiency**
- Sinus infections and other respiratory infections
- Digestive tract infections
- Ear infections
- Pneumonia
- Bronchitis
- Infections that result in sore throat
- Severe and life-threatening infections (rare)

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People who have recurrent infections due to a primary immune deficiency sometimes go without an accurate diagnosis for months and even years. When an immunologic workup is ordered, total quantitative IG levels of all classes and IgG subclasses are included. If the evaluation of immune response with various vaccines shows a good response, treatment may only consist of treating infections as they occur, while continuing to monitor IG and other laboratory values to see
Grifols’ XEMBIFY Now Available to Treat PI

Grifols’ first 20% subcutaneous immune globulin (SCIG) to treat primary immunodeficiency disease (PI) patients is now available in the U.S. XEMBIFY is approved by the U.S. Food and Drug Administration to treat PI patients 2 years of age and older. The SCIG product provides a customizable IG treatment option from weekly to daily. It is available from the following providers: Advanced InfusionCare; Nufactor, a Specialty Infusion Company; CVS/Specialty; Optum Infusion Services; and Accredo.

“Today marks an exciting milestone as we launch XEMBIFY, an important medicine for PI patients in the United States,” said Joel Abelson, president of Bioscience Commercial Division. “Adding to our existing IG portfolio, XEMBIFY is another example of Grifols executing on our mission to improve the lives and well-being of people who suffer from serious, rare and chronic diseases.”


Research

Pediatric PI Patients Eligible to Enroll in Yale Genomics Study

As part of its Pediatric Genomics Discovery Program, Yale University is conducting a study to discover the genetic mutations responsible for inherited immune diseases and to perform follow-up studies about how the mutations affect cell function. Children under age 18 years who have a biological mom and dad who can provide researchers with blood samples are eligible to participate in the study. Participants will be asked for blood draws and to complete a clinical health survey and/or medical questionnaire. There is no cost to enroll in the study, nor compensation for participation.

More information can be obtained about the study from Carrie Lucas, PhD (carrie.lucas@yale.edu; 203-785-7158), or Andrew Rice (a.rice@yale.edu; 203-737-7425). Immune Deficiency Foundation. Yale Genomic Testing and Research Study for Children Affected by Primary Immune Deficiencies (PID). Accessed at primaryimmune.org/sites/default/files/YaleStudyFlyer.pdf.

Hizentra Found to Be a Noninferior Option to Previous IVIG/SCIG-Based Treatment for Pediatric PI Patients

Results of the Infusione Bimensile di Immunoglobuline Sottocute (IBIS) study that investigated the effects of Hizentra (subcutaneous immune globulin [SCIG], human, 20%) administered biweekly in patients with primary immunodeficiency disease (PI) showed it is a noninferior option compared with previous intravenous IG (IVIG) and SCIG-based treatment. In the study, 13 children with PI were observed for 12 months retrospectively (with previous IVIG/SCIG) and prospectively with biweekly Hizentra. Results showed mean plus or minus standard deviation serum IG levels during the retrospective (833.8 ± 175.7 mg/dL) and the prospective (842.0 ± 188.0 mg/dL) phases were comparable. There were also no differences in the number of infections.

RMS Medical Products has rebranded as KORU Medical Systems. “Our decision to rebrand the company reflects the great strides we have made in evolving our corporate culture, mission and philosophy to a more patient-centric focus,” said Don Pettigrew, president and CEO. “The rebranding is inspired by the koru, a widely recognized symbol of a spiral-shaped, unfurling fern that represents new life and new beginnings. KORU Medical Systems’ focus on providing patients’ new beginnings with our at-home infusion systems is at the heart of our brand.”

On Oct. 24, 2019, the company’s email address changed to the domain @korumedical.com and its homepage is now www.korumedical.com.

Research

Adjuvant IVIG Significantly Reduces Viral Load in Immunocompromised Patients with Severe Varicella

A recent case study found five-day adjuvant intravenous immune globulin (IVIG) therapy significantly reduces viral load in immunocompromised patients with severe varicella. While varicella zoster virus (VZV) is usually a self-limited disease in immunocompetent patients, it can be fatal for immunocompromised patients such as organ transplant recipients. And, while there are few reports of whether IVIG would benefit immunocompromised patients with varicella, the researchers noted IVIG could suppress viremia by preventing invasion of VZV into target cells.

In the case study, a 21-year-old woman who had received a living-related kidney transplant one year prior presented with fever and a generalized multi-rash for five days. She was diagnosed with chickenpox and treated with intravenous acyclovir (ACV) for two days, but fulminant hepatitis due to VZV progressed despite ACV therapy. She was then admitted to a different hospital where she was administered adjuvant IVIG with intravenous ACV therapy, and her condition gradually improved. After infusion of IVIG for five days, serum creatinine increased.

According to the researchers, “Considering the cause of elevated serum creatinine, IVIG might not be excluded. The use of IVIG must be carried out with care because renal toxicity following IVIG infusion is not uncommon. Also, infusion of IVIG may lead to several complications such as anaphylaxis, central nerve system complications, thromboembolism, hemolysis, and neutropenia. A previous study showed that current IVIG preparations have high levels of VZV-specific IgG despite waning immunity to VZV in the general population due to the lack of circulating virus. However, there are few data on whether IVIG can suppress viremia by neutralizing VZV. Despite continuous ACV infusion, the slope of blood viral load was steeper during the five-day IVIG infusion than that after the infusion. Furthermore, we clearly showed that VZV-specific T cell and antibody responses were not mounted up to the end of the IVIG infusion, which means that the patient’s own immune response was not yet able to control the disseminated VZV during the IVIG therapy. Previous studies have shown that VZV-specific IgG antibody is detected in most patients within the first four days after the onset of rash. In addition, viral load in peripheral blood in patients with varicella rapidly decline one week after the onset of symptom. We assume that the immunocompromised status may have contributed to the delayed antibody response and viral clearance in this patient. We believe that this case provides important experimental evidence that adjuvant IVIG can significantly reduce viral load kinetics in immunocompromised patients with severe varicella.”


Important Safety Information

WARNING: Thrombosis (blood clots) can occur with immune globulin products, including Hizentra. Risk factors can include: advanced age, prolonged immobilization, a history of blood clotting or hyperviscosity (blood thickness), use of estrogens, installed vascular catheters, and cardiovascular risk factors.

If you are at high risk of blood clots, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor for signs of clotting events and hyperviscosity. Always drink sufficient fluids before infusing Hizentra.

See your doctor for a full explanation, and the full prescribing information for complete boxed warning.

Hizentra is a prescription medicine used to treat:

- Primary immune deficiency (PI) in patients 2 years and older
- Chronic inflammatory demyelinating polyneuropathy (CIDP) in adults

Treatment with Hizentra might not be possible if your doctor determines you have hyperprolinemia (too much proline in the blood), or are IgA-deficient with antibodies to IgA and a history of hypersensitivity.

Tell your doctor if you have previously had a severe allergic reaction (including anaphylaxis) to the administration of human immune globulin. Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Inform your doctor of any medications you are taking, as well as any medical conditions you may have had, especially if you have a history of diseases related to the heart or blood vessels, or have been immobile for some time. Inform your physician if you are pregnant or nursing, or plan to become pregnant.

Infuse Hizentra under your skin only; do not inject into a blood vessel. Self-administer Hizentra only after having been taught to do so by your doctor or other healthcare professional, and having received dosing instructions for treating your condition.

Immediately report to your physician any of the following symptoms, which could be signs of serious adverse reactions to Hizentra:

*lg=immunoglobulin
Reduced urination, sudden weight gain, or swelling in your legs (possible signs of a kidney problem).

Pain and/or swelling or discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness/weakness on one side of the body (possible signs of a blood clot).

Bad headache with nausea; vomiting; stiff neck; fever; and sensitivity to light (possible signs of meningitis).

Brown or red urine; rapid heart rate; yellowing of the skin or eyes; chest pains or breathing trouble; fever over 100°F (possible symptoms of other conditions that require prompt treatment).

Hizentra is made from human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

The most common side effects in the clinical trials for Hizentra include redness, swelling, itching, and/or bruising at the infusion site; headache; chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible. Tell your doctor about any side effect that bothers you or does not go away.

Before receiving any vaccine, tell immunizing physician if you have had recent therapy with Hizentra, as effectiveness of the vaccine could be compromised.

Please see brief summary of full prescribing information for Hizentra on adjacent page. For full prescribing information, including boxed warning and patient product information, please visit Hizentra.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

You can also report side effects to CSL Behring’s Pharmacovigilance Department at 1-866-915-6958.
HIZENTRA®, Immune Globulin Subcutaneous (Human), 20% Liquid
Initial U.S. Approval: 2010
BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use HIZENTRA safely and effectively. See full prescribing information for HIZENTRA.

WARNING: THROMBOSIS
See full prescribing information for complete boxed warning.

- Thrombosis may occur with immune globulin products, including HIZENTRA. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.
- For patients at risk of thrombosis, administer HIZENTRA at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

INDICATIONS AND USAGE
HIZENTRA is indicated for:
* Treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years and older.
* Maintenance therapy in adults with chronic inflammatory demyelinating polyneuropathy (CIDP) to prevent relapse of neuromuscular disability and impairment.

LIMITATION OF USE: Maintenance therapy in CIDP has been systematically studied for 6 months and for a further 12 months in a follow-up study. Continued maintenance beyond these periods should be individualized based on patient response and need for continued therapy.

For subcutaneous infusion only.

DOSEAGE FORMS AND STRENGTHS
0.2 g per mL (20%) protein solution for subcutaneous injection

CONTRAINDICATIONS
- Anaphylactic or severe systemic reaction to human immune globulin or components of HIZENTRA, such as polysorbate 80
- Hyperprolinemia (type I or II) (HIZENTRA contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

WARNINGS AND PRECAUTIONS
- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions.
- Thrombosis may occur following treatment with immune globulin products, including HIZENTRA.
- Aseptic meningitis syndrome has been reported with IGIV or IGSC, including HIZENTRA treatment.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of acute renal failure.
- Monitor for clinical signs and symptoms of hemolysis.
- Monitor for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).
- HIZENTRA is made from human plasma and may contain infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

ADVERSE REACTIONS
The most common adverse reactions observed in ≥5% of study subjects were local infusion site reactions, headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, upper respiratory tract infection, rash, pruritus, vomiting, abdominal pain (upper), migraine, arthralgia, pain, fall and nasopharyngitis.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS
The passive transfer of antibodies may interfere with the response to live virus vaccines, and lead to misinterpretation of the results of serological testing.
Guidelines
New Practice Guidelines Now Available for ITP

The American Society of Hematology (ASH) has published new state-of-the-art guidelines for the treatment of immune thrombocytopenia (ITP), a rare bleed disorder characterized by a decrease in the number of platelets, the part of the blood needed for normal clotting. The 2019 ASH Clinical Practice Guidelines on ITP, developed in partnership with the University of Oklahoma Health Sciences Center, synthesize all available evidence about existing treatments to offer recommendations for disease management in both children and adults. Notably, these new guidelines address appropriate corticosteroid use in adults and stress avoiding unnecessary treatment in children. They also tackle the complex decision-making surrounding second-line agents. They are intended to help hematologists educate other physicians who provide care to people with ITP and aid in shared patient-physician decision making. Where evidence gaps exist, the guidelines make recommendations for future research.

“Through these guidelines, ASH is helping to ensure that physicians and patients have access to all of the evidence available so they can evaluate various treatment options and make an informed decision using the guideline recommendations as a foundation for care,” said Cindy Neunert, MD, chair of the ASH ITP guideline panel and a hematologist at New York-Presbyterian Hospital in New York City. “The guidelines also equip hematologists, the experts in ITP, to educate other providers who often see these patients first such as emergency room physicians, pediatricians or primary care physicians who are often less familiar with this disease and its treatments.”

The guidelines are an update from those ASH published in 2011. They are the most recent product of a larger guideline development initiative for ASH, which includes a commitment to the timely update of existing guidelines and the development of new ones on a range of hematologic conditions. Resources to aid in the implementation of the guidelines have been added to the ASH website.

Research
Infliximab Recommended as Second-Line Therapy in IVIG-Refractory KD Patients

A study that evaluated the efficacy and safety of three treatments (a second intravenous immune globulin [IVIG] infusion, methylprednisolone [IVMP] and infliximab [IFX]) in patients with refractory Kawasaki disease (KD) found that, in the absence of a clinical trial, IFX monotherapy as second-line treatment should be taken into consideration for people who fail to react to initial IVIG.

The study included a systematic search of PubMed, Embase, Cochrane and ClinicalTrials.gov using predefined medical subject headings terms from 1990 through 2017. Eight studies met the inclusion criteria. Of the 388 patients included from the eight studies analyzed, a majority (68 percent) received a second IVIG dose. Fever resolution was comparable between IVIG (72 percent) and IVMP (73 percent). However, IFX (88 percent) significantly increased fever resolution by approximately 20 percent compared to IVIG redose and IVMP. Clinical significance of differences in coronary outcomes remains unclear.

Managing Care During Immune Globulin Product Shortages

Understanding the reasons behind the shortages and what to do during these periods can help patients gain access to their lifesaving treatment.

By Rachel Colletta, BSN, CRNI, IgCN, VA-BC, and Luba Sobolevsky, PharmD

RECENT SHORTAGES of immune globulin (IG) products are impacting the care and treatment of patients across the U.S. and worldwide. It is likely some patients are currently affected by the limited availability of a specific product. What are some of the factors that contribute to limited product availability, and how can patients navigate the bumpy roads of product shortages?

What Causes Shortages?
IG products are derived from human plasma, which is the clear liquid part of blood that contains proteins like immunoglobulin, albumin, clotting factors and many others. Manufacturing of plasma proteins is complicated and very expensive, taking between nine and 12 months from the time plasma is collected to the finished product. This process involves a series of intricate steps designed to produce a highly purified product that is safe and effective. Interruptions in the manufacturing process, the plasma collection process or any issues with the final product can result in a disruption of supply. Also, brief delays in new product approvals by the U.S. Food and Drug Administration (FDA) or temporary product (or specific lot) withdrawals from the market can negatively impact supply and, therefore, patient access to this lifesaving therapy.
The manufacture of plasma products is completely dependent on human donors for its raw material. Plasma donors in the U.S. go through a rigorous screening process to ensure they are healthy and meet all the strict selection requirements. At the present time, there is an acute need for more plasma donations to increase the supply of this valuable raw material.

The need for IG products is expected to continue to grow each year. New indications, increased off-label usage and earlier diagnoses are a few of the factors driving this growth. Indeed, the Plasma Protein Therapeutics Association reports there was a 66 percent increase in IG use between 2012 and 2018 across North America and Europe. More than 88 million grams of IG were administered to more than 200,000 patients receiving therapy. This expansion of demand also contributes to IG supply problems.

In August 2019, FDA released a statement addressing the issues of product shortages along with a list of the products with limited availability. FDA cited increased demand for IG products with a supply that is not able to keep pace as the reason for the shortages. Its recommendations for healthcare providers are to develop a system to determine which patients should receive priority treatment and to consider adding additional products to their formularies to use during times of shortages.

During these periods of shortages, it is extremely important for patients to understand their options. With this knowledge, patients can be their own advocates to help navigate the bumpy roads of limited product availability.

Managing Therapy Through Shortages

It can be a stressful time when patients learn they may not receive their scheduled treatment. Feeling they have somehow lost control over their healthcare can be frightening. However, patients can take back that control by advocating for themselves and by working closely with their healthcare team and insurance providers. Also, having knowledge of the other available product alternatives may help in making decisions regarding a change in IG brand or route of administration, should either become necessary.

As each IG product is unique, there are no generics. And, while all IG products are considered effective for treating various disease states, patients should be knowledgeable about the specific product attributes that may have an effect on personal, patient-specific side effects. Organizations like the Immunoglobulin National Society (www.ig-ns.org) and patient foundations provide free resources (Table) that increase knowledge and awareness about currently available products.

Because each product is unique and every patient is different, patients can experience different side effects from product to product. Sodium, sugar and other additives can also increase the incidence of serious adverse events such as kidney issues, stroke or heart attack. In the event of an IG shortage, working closely with a nurse, pharmacist and physician to determine which product is the best fit can make the transition to a new product safer.

A change in the route of administration is another option to consider during product shortages. Transitioning from intravenous IG (IVIG) to subcutaneous IG (SCIG) therapy, or vice versa, can help bridge the gap until the preferred product becomes available again.

Changing to SCIG requires careful planning and preparation to ensure a successful transition. SCIG is self-administered by the patient or caregiver. This type of therapy is traditionally administered once per week; however, depending on the dose, it may need to be administered more often. SCIG requires willingness on the part of patients to self-administer on a consistent basis to maintain therapeutic levels of immunoglobulins in their bodies. Keeping a regular self-administration schedule without missing doses is a critical part of successful SCIG therapy. In addition, self-administration of SCIG requires the ability to work with equipment and administration sets. Patients who cannot operate the equipment, have a fear of needles or vision issues, or those who do not have anyone to assist them if any difficulties take place, should avoid SCIG.

The differences in IG products make it necessary to take extra care during the first several infusions when a new product is started. A nurse will carefully observe each patient, and the infusion rate will need to be slower than usual until it is known how the patient feels on the new product. A healthcare
### Table. U.S. Food and Drug Administration-Approved Immune Globulin Products

<table>
<thead>
<tr>
<th>Product</th>
<th>Manufacturer</th>
<th>Route</th>
<th>FDA-approved Indication(s)</th>
<th>IgA Content (mcg/mL)</th>
<th>pH</th>
<th>Sodium Content (mEq/L)</th>
<th>Stabilizer</th>
<th>Osmolality/ Osmolarity (mOsm/kg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asceniv 10%</td>
<td>ADMA Biologics</td>
<td>IV</td>
<td>PI in adults and adolescents (12 years-17 years)</td>
<td>200</td>
<td>4.0-4.6</td>
<td>100-140 (0.10-0.14 M)</td>
<td>Glycine, Polysorbate 80</td>
<td>Not listed</td>
</tr>
<tr>
<td>Bivigam 10%</td>
<td>ADMA Biologics</td>
<td>IV</td>
<td>PI in adults</td>
<td>200</td>
<td>4.0-4.6</td>
<td>100-140 (0.10-0.14 M)</td>
<td>Glycine, Polysorbate 80</td>
<td>Not listed</td>
</tr>
<tr>
<td>Cubiquig 16.5%</td>
<td>Octapharma</td>
<td>SC</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>80</td>
<td>4.6-5.1</td>
<td>No added sodium</td>
<td>Glycine</td>
<td>280-292</td>
</tr>
<tr>
<td>Cuzli 20%</td>
<td>Takeda</td>
<td>SC</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>Typically &lt;50</td>
<td>5-6</td>
<td>Trace amounts</td>
<td>Sorbitol</td>
<td>240-370</td>
</tr>
<tr>
<td>Rebagamma 5% DIF</td>
<td>Gritols</td>
<td>IV</td>
<td>PI</td>
<td>Typically &lt;100</td>
<td>5-6</td>
<td>Trace amounts</td>
<td>Sorbitol</td>
<td>240-370</td>
</tr>
<tr>
<td>Rebagamma 10% DIF</td>
<td>Gritols</td>
<td>IV</td>
<td>PI Chronic ITP in patients 2 years and older</td>
<td>Typically &lt;100</td>
<td>5-6</td>
<td>Trace amounts</td>
<td>Sorbitol</td>
<td>240-370</td>
</tr>
<tr>
<td>Gammagard Liquid 10%</td>
<td>Takeda</td>
<td>N, SC (IV) PI in adults and pediatric patients 2 years and older</td>
<td>&lt;1 (5%)</td>
<td>&lt;2 (10%)</td>
<td>6.8±0.4</td>
<td>146 [5% (8.5mg/ml)]</td>
<td>Gluten, Glycine</td>
<td>630-55% From Monograph ~1250 (10%) From Monograph</td>
</tr>
<tr>
<td>Gammagard S/D (5% or 10% when reconstituted)</td>
<td>Takeda</td>
<td>N</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>CLL</td>
<td>6.6±0.4</td>
<td>146 [5% (8.5mg/ml)]</td>
<td>Gluten, Glycine and Polysorbate 80</td>
<td>Not &lt; 240 (Typically 420-500)</td>
</tr>
<tr>
<td>Gammaked 10%</td>
<td>Kedrion</td>
<td>N, SC</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td></td>
<td>46</td>
<td>4.0-4.5</td>
<td>Not listed</td>
<td>Glycine</td>
</tr>
<tr>
<td>Gammexar 5%</td>
<td>BPL</td>
<td>IV</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>&lt;10</td>
<td>4.8-5.1</td>
<td>Not listed</td>
<td>Sorbitol, Glycine and Polysorbate 80</td>
<td>Not &lt; 240 (Typically 250)</td>
</tr>
<tr>
<td>Gammagard 10%</td>
<td>BPL</td>
<td>IV</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>&lt;20</td>
<td>4.9-5.2</td>
<td>&lt;30</td>
<td>Glycine and Polysorbate 80</td>
<td>Not &lt; 240 (Typically 250)</td>
</tr>
<tr>
<td>Gamunex-C 10%</td>
<td>Gritols</td>
<td>N, SC</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>Chronic ITP in adults</td>
<td>46</td>
<td>4.0-4.5</td>
<td>Not listed</td>
<td>Glycine</td>
</tr>
<tr>
<td>Hiemotra 20%</td>
<td>CSL Behring</td>
<td>SC</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>CDP in adults (Maintenance therapy)</td>
<td>&lt;50</td>
<td>4.6-5.2</td>
<td>Trace amounts</td>
<td>L-proline</td>
</tr>
<tr>
<td>HyQvia 10%</td>
<td>Takeda</td>
<td>SC</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>CLL</td>
<td>4.6-5.1</td>
<td>No sodium added</td>
<td>Glycine</td>
<td>240-300</td>
</tr>
<tr>
<td>Octagam 5%</td>
<td>Octapharma</td>
<td>N</td>
<td>PI</td>
<td>200</td>
<td>3.1-6.0</td>
<td>&lt;30</td>
<td>Maltose</td>
<td>310-380</td>
</tr>
<tr>
<td>Octagam 10%</td>
<td>Octapharma</td>
<td>N</td>
<td>Chronic ITP in adults</td>
<td>106</td>
<td>4.5-5.0</td>
<td>&lt;30</td>
<td>Maltose</td>
<td>310-380</td>
</tr>
<tr>
<td>Pariplas 10%</td>
<td>Octapharma</td>
<td>N</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>Chronic ITP in adults</td>
<td>100</td>
<td>4.5-5.0</td>
<td>Trace amounts</td>
<td>Glycine</td>
</tr>
<tr>
<td>Privigen 10%</td>
<td>CSL Behring</td>
<td>N</td>
<td>PI in adults and pediatric patients 2 years and older</td>
<td>Chronic ITP in patients 15 years and older</td>
<td>&lt;25</td>
<td>4.6-5.0</td>
<td>Trace amounts</td>
<td>L-proline</td>
</tr>
<tr>
<td>Xembify 20%</td>
<td>Grifols</td>
<td>SC</td>
<td>PI in patients 2 years and older</td>
<td>Not listed</td>
<td>4.1-4.8</td>
<td>Not listed</td>
<td>Glycine, Polysorbate 80</td>
<td>280-404</td>
</tr>
</tbody>
</table>

PI = Primary Immunodeficiency  
ITP = Immune Thrombocytopenia  
CIDP = Chronic Inflammatory Demyelinating Polyneuropathy  
CLL = Chronic Lymphocytic Leukemia  
KD = Kawasaki Disease  
MMN = Multifocal Motor Neuropathy
provider should provide education about possible reactions, how to lessen their severity and when and how to report any reaction that may occur hours or days after the infusion.

Site-of-Care Considerations
During shortages, facilities or providers may have different access to IG therapies, and not all may be experiencing supply interruptions. Patients should know their options and be able to switch where and how they receive IG during product shortages. Understanding site-of-care options may allow patients to continue to receive IG therapy without interruption. For example, patients receiving IG therapy in the home may be able to continue service uninterrupted at a local infusion center. And, some patients receiving treatment at an infusion center may be able to continue therapy in the home.

Insurance Considerations
Changes in product or site of care will likely require prior authorization from patients’ insurance. To facilitate any changes, patients’ healthcare providers should work with them to minimize the interruption of therapy as much as possible. Payers often have preferred brands and contracts that limit patient access to certain brands of products. Requests for changes are occasionally denied and then must go through an appeal process. Establishing open communication with a representative from the insurance company may help provide it with additional insight for how best to meet patients’ needs.

The Importance of Plasma
Plasma is a finite resource, and there is no substitute for this precious liquid. As the use of IG and other plasma proteins increases, it is vital the supply continues to grow as well. Plasma donors are compensated for their time in the U.S., which has allowed our country to supply many more patients than in other countries. Plasma donors must meet specific criteria and may donate up to two times per week with a 48-hour break between donations (Figure).

Plasma donation is a commitment for individuals who choose to give their time in this way. Without regular donations from qualified donors, the supply of plasma products would cease to exist. As the primary and only source of supplying hundreds of thousands of patients in the U.S alone with the therapies they need to survive, these invisible heroes are saving lives with every single donation. If patients know someone who is a plasma donor, they should thank them. If they have friends and family who can donate, they should ask them. For more information about the plasma donation process, visit www.donatingplasma.org.

RACHEL COLLETTA, BSN, CRNI, IgCN, VA-BC, is director of educational resources at the Immunoglobulin National Society, a professional organization dedicated to the advancement of immune globulin therapy across clinical indications and areas of practice. LUBA SOBOLEVSKY, PharmD, is the founding executive director of the Immunoglobulin National Society. She holds a doctor of pharmacy degree from the University of Southern California, and has expertise across various fields in healthcare, including the clinical, educational development and pharmaceutical industry.

Resources
1. Plasma Protein Therapeutics Association: www.pptaglobal.org

Editor’s note: The original table contains dosing information for the IG products. To obtain a copy of the original table, contact the Immunoglobulin National Society at (888) 855-4443 or info@Ig-NS.org.
The Importance of Properly Trained INFUSION NURSES

Patients can take a proactive role in their care by understanding the specialized training required for nurses to safely infuse immune globulin therapy.

By Abbie Cornett
INFUSIONS ARE NEVER easy! However, the difference between a positive and negative experience can depend on how well the infusion nurse was trained. And, while patients often assume all infusion nurses have the same training and skills to administer treatment, that is not always the case. Keeping this in mind, patients should take an active role in understanding what training is required to be a qualified infusion nurse and just how critical that training is.

What Is an Infusion Nurse?

During the 1980s in an effort to contain rising healthcare costs, especially those associated with intravenous infusion therapies, the medical community moved treatments out of the hospital setting and into alternative settings. This move was made possible with technological advances in clinical administration, most specifically the development and specialization of the infusion nursing field, which allowed patients to receive safe and effective treatment either at home or in an outpatient infusion center. These alternative settings not only saved money, they improved patients’ quality of life.¹

Infusion nurses are registered nurses who specialize in the administration of medications and fluids through an intravenous (IV) line, central line or venous access port. While infusion nurses have many roles, their primary job is to ensure the safety of patients. To fulfill that role, they must be experts in all things that affect patient outcomes. Their knowledge should include but is not limited to infusion needles and catheters, a strong understanding of venous anatomy, an awareness of the physiology of fluid balance and the ability to think critically and respond to emergencies.² Further, infusion nurses must receive appropriate training in choosing the correct site for insertion of the catheter, be able to identify signs of infection or infiltration and watch for indications of blood clots, thrombosis within the vein or an allergic reaction to the medication. Overall, they need to ensure patients’ comfort during their infusion therapy, and have the skills to work in a variety of healthcare settings, including home care, acute care and infusion centers.³

Not All Infusions Are the Same

Infusion therapy involves the administration of medication through a needle to treat a variety of conditions that cannot be treated with oral medications. However, all infused medications do not require the same skill set. Treatments can range from the less complex administration of hydration
therapy, to the very complex administration of injectable biologics such as immune globulin (IG).

IG is derived from donated human plasma. Historically, it was first prescribed for patients with primary humoral immune deficiency diseases. Now, it is used to treat a wide array of diseases such as chronic inflammatory demyelinating polyneuropathy, peripheral neuropathy, myasthenia gravis, Guillain-Barré syndrome, multiple sclerosis, polymyositis and dermatomyositis, among others. Nurses who infuse IG must receive training in the clinical uses for this lifesaving medication, as well as be familiar with the diseases treated with it. Nurses must also be knowledgeable about potential side effects, the precautions to take to prevent them and how to mitigate them if they occur.

According to Roger Kobayashi, MD, clinical professor at the University of California, Los Angeles School of Medicine and an allergist-immunologist in Omaha, Neb., the importance of having a highly qualified infusion nurse to mitigate some of the inherent problems that can pose risk to patients receiving IG therapy cannot be overstated. Simply being familiar with the infusion of pharmacologics is not adequate experience for these nurses since biologic preparations such as IG are much more complex and they come with unique risks. This is especially true for infusion nurses treating patients in a nonclinical environment such as the home setting. These nurses must have advanced knowledge of possible adverse reactions associated with the medication, and they must be able to immediately spot the early warning signs of adverse reactions. Untrained nurses may not recognize these signs and thus expose patients to significant risk.

Administration of IG

IG can be administered in two ways: intravenously (IVIG) and subcutaneously (SCIG). Unlike IVIG, which is infused into a vein, SCIG is infused by slowly injecting the medicine into fatty tissue just underneath the skin. According to Dr. Kobayashi, infusion nurses must be well-trained in infusing both IVIG and SCIG, and fully knowledgeable about the different dosing requirements of each. They must also understand that no two IG products are the same, and how each product differs in preparation, stabilizers and IgA content.

While most patients tolerate IG replacement therapy well, both IVIG and SCIG can have side effects. With IVIG, up to half of all patients experience at least one adverse side effect such as headache, low-grade fever, aching muscles or joints and rashes. These are especially likely to occur if patients are not receiving IVIG on a regular basis and/or if they are receiving higher doses of IVIG.4 In addition, IVIG patients have a greater risk of thrombosis because infusions are administered through vein access. And, while the majority of side effects are usually minor, more serious side effects like anaphylactic shock, aseptic meningitis or blood clots can occur. With SCIG, the severity of side effects is mostly reduced or eliminated since the medicine is absorbed by the body more slowly through fatty tissue, rather than in large doses entered directly into the circulatory system.

Prior to infusions, nurses must be aware of all risk factors that can affect patients’ outcomes such as their health history, age, product integrity and status. Some factors that can

What Is Infusion Therapy?

According to the National Home Infusion Association, infusion therapy involves the administration of medication through a needle or catheter. It is prescribed when a patient’s condition is so severe it cannot be treated effectively by oral medications. Typically, infusion therapy means a drug is administered intravenously, but the term also may refer to situations in which drugs are provided through other nonoral routes such as intramuscular injections and epidural routes (into the membranes surrounding the spinal cord).
contribute to adverse reactions are diabetes, renal dysfunction, age (65 and older), coronary artery disease, hypertension, cerebrovascular disease, hyperviscosity disorder (including multiple myeloma, macroglobulinemia and polycythemia), thrombotic events and peripheral vascular disease.\(^5\)

Also prior to infusion, nurses must log the blood product, lot number(s), expiration dates and dosages in each patient’s record and a central database. And, they must be knowledgeable and able to communicate effectively to notify doctors, pharmacists and/or others involved in patients’ care about real or potential risks for them.

Finally, if patients experience an adverse reaction while receiving an infusion, the details must be documented. And, whenever patients experience an adverse reaction to IVIG, a new consent form must be completed. If patients do not tolerate IVIG therapy, they may benefit from switching to SCIG therapy.

**Education Requirements**

It’s critical patients receiving infusion therapies understand the expertise and specialized training infusion nurses must have. While all nurses learn the basics of infusions and how to start IVs, infusion nurses must acquire additional specialized knowledge through continued education and training.

Below are the basic educational requirements for registered nurses who work as infusion nurses:\(^6\)

1) A diploma in nursing (associate’s degree, bachelor’s degree or master’s degree)
2) A passing grade on the National Council Licensure Examination
3) Work experience as a registered nurse for at least one year
4) Exposure in an infusion-related department as a registered nurse (minimum requirement is 1,600 hours or two months total)

In addition to the basic requirements, there is also a premium certification for infusion nursing. The Infusion Nurses Society provides a rigorous and comprehensive exam registered nurses can take to receive a Certified Registered Nurse Infusion (CRNI) certificate. The exam covers the core areas of infusion nursing, which are the principles of practice, access devices and infusion therapies. The CRNI certificate validates the knowledge and skills these nurses have acquired and indicates those nurses are experts in the infusion field.

It should be noted that while there can be a significant difference in the care patients receive from a certified infusion nurse, many nurses without certification have the experience necessary to provide excellent quality care.

**Ensuring Care**

Clearly vital to the patient experience, infusion nurses must be experts in infusion needles and catheters, critical thinking, responding to emergencies, anticipating what could go wrong and mitigating such issues. Patients deserve nothing less than the safest and best possible care when receiving infusions. As quality of their care directly relates to the education and training of their infusion nurses, it behooves patients to be informed about the proper training required for infusion nurses and to know what to expect from them so all can work together to achieve the best possible patient care.

**ABBIE CORNETT** is the patient advocate for IG Living magazine.

**References**

A Guide to Decoding Medical Bills

Becoming familiar with the types of receipts, bills and terminology used in healthcare can help patients avoid paying for billing mistakes.

By Jim Trageser
TACKLING BILLING  paperwork for medical care is certainly not the worst part of dealing with a chronic illness, but it does add to what is already a very stressful situation. The structure of bills can be confusing, explanations are usually full of unfamiliar jargon and prices can seem disconnected from reality. Fortunately, numerous resources are available to assist patients and their families in making sense of what they’re being charged so, in the event of a dispute, they are at least able to operate from a position of relative knowledge.

And, patients are likely going to need that knowledge since recent studies indicate 80 percent to 90 percent of bills reviewed contain a billing error, adding up to some $68 billion a year in illegitimate charges. Therefore, patients clearly need to be informed and vigilant to protect their financial health while also dealing with their physical health.

Getting Organized

When dealing with a chronic disease or condition involving frequent doctor, clinic and hospital visits, there are going to be a lot of bills. And, there will be a lot of other forms and paperwork, too.

Specifically, there are three financial forms associated with each medical visit that should be tracked and reconciled:

1) A receipt from the doctor’s office, clinic or hospital the day of the exam detailing treatment received and containing the International Classifications of Diseases (ICD)-10 codes they will use to bill insurance. Patients should be sure to ask for this before they leave.

2) The insurance company’s explanation of benefits (EOB) detailing what the doctor, clinic or hospital is claiming for that visit. This is typically sent by mail or email to patients a week or two after the visit.

3) The actual bill. There may be multiple bills from a single hospital visit since the doctors and labs may be separate business entities.

The best way to navigate financial forms and ensure there are no overcharges is for patients to get organized. It is important to be able to tie visits to bills to ensure patients pay only for services received.

The American Society of Clinical Oncology has created a guide for tracking and checking medical bills. Its website, Cancer.net, suggests marking every appointment on a calendar and keeping a log of all tests and procedures performed each visit. Also, every prescription should be listed, including the name of the drug, prescribing physician and the dosage and amount prescribed (number of pills or volume of liquid). This is also true for shots, pills or liquid prescriptions given by the doctor or nurse during a visit since patients will be billed for those as well.

With this information, patients can then start charting the treatment received against what is billed. This can be a handwritten chart or a computer spreadsheet. (Making it even easier for users of Microsoft Office is a free template form designed for its Excel spreadsheet that can be downloaded at templates.office.com/en-us/Patient-s-medical-bill-tracker-TM01071388.)

Patients will also want to have a system for saving all paperwork so, if there is a dispute, they have the documentation to back up their position. Visit receipts should be stapled or paperclipped to the insurance forms and the eventual bill for that visit, and they should be safely stored for at least three years (since medical costs are generally deductible on federal and state taxes).

What the Law Says

Hospitals, clinics and doctor office billing practices are governed by a variety of laws that require certain disclosures to patients. One of the most important laws is the Health Insurance Portability and Accountability Act (HIPAA). Passed by Congress in 1996 (and updated since), HIPAA declared patients’ medical information belongs to them. Therefore, patients have the right to see a copy of all protected health information (PHI) a doctor, hospital or insurance company has on file about them, including an itemized version of any bill with a line-by-line breakdown of all charges being assessed. Further, if patients request a digital copy of their PHI, they cannot be charged for it. However, the billing agency is allowed to charge a reasonable fee to cover the cost of printing a physical copy.
Another important part of HIPAA is an update that dictates medical bills use ICD-10 codes for diagnoses and treatment. ICD-10 is a very detailed list of all diagnoses and procedures for which a doctor can bill. Every bill must include an ICD-10 code for each charge. There are numerous free online sources where patients can look up ICD-10 codes to ensure they match what is included on their receipt and/or bill. For instance, at www.icd10data.com, patients can type in the code from their bill and find exactly what the diagnosis or procedure is.

Also under HIPAA, upon completion of any medical visit, patients are entitled to a printed list of all procedures conducted. While patients will likely not receive an actual bill that day, they should never leave the office without an official record of what was done: exam, tests, injections, drugs administered, referrals, etc.
Before leaving the clinic, doctor office or hospital, patients should look over the treatment record to make sure it reflects what they experienced or observed (although it may be just a list of ICD-10 codes since there is no law requiring bills or records must be easy to understand). If patients have any questions about what is on a receipt, they should raise their concerns at that time. It is much more difficult to have that receipt corrected after the fact.

**What Is Owed**

After a doctor visit and before the bill arrives, patients will receive an EOB from their insurance company. Cigna Insurance on its website defines an EOB as “a statement of the medical services you received and details on how you and your plan will share costs.”

Patients should compare their EOB to their calendar or journal entry for that visit, as well as their visit receipt, and make sure the insurance company was accurately billed for the treatment received. Every ICD-10 code on the EOB should be compared with their appointment record, and they should match.

Specifically, patients should check these items on the EOB for accuracy:

- Is the patient’s name spelled correctly? (Claims can be denied for misidentification.)
- Are the facilities all correctly identified as in-network?
- Are co-pays accurate?

The EOB will also list how much the insurance company is paying, as well as any balance the patient owes (if any). Progress toward meeting the policy’s deductible will also be noted.

If patients have any doubts about the accuracy of the EOB’s financial statements, they should contact their insurer immediately.

When the bill itself arrives, it should be compared to the EOB. Patients should only be billed for what the EOB indicates the patient owes. Again, if there is any discrepancy, the insurer and doctor’s office, clinic or hospital that sent the bill should be contacted immediately.

**Know the Terminology**

Patients need to understand terminology used on bills, and this is where things can get the most confusing. As mentioned previously, there is no law that requires doctor offices, clinics or hospitals to use plain English when billing patients or their insurance companies.

However, many insurers now post a glossary of terms on their website to assist patients. Cigna’s glossary is located at www.cigna.com/glossary, while Blue Cross/Blue Shield’s glossary is located at www.bcbs.com/learn/glossary. Each insurer may use slightly different terminology, or it may use it differently, so while most terms (see Common Terms on EOBs and Medical Bills) are generally understood, patients are advised to check their own insurer’s glossary. Many insurers include a glossary with their EOB or their annual policy statement.

Diligence Will Prove Worthwhile

With the staggering amount of money billed for illegitimate charges, patients must perform due diligence before paying medical bills. This means documenting visits and double-checking for consistency among visit receipts, EOBs and bills. By doing so and making an effort to understand the confusing terminology used by the healthcare industry, patients can ensure they keep as much of their hard-earned money as possible in their own pockets.

**JIM TRAGESER** is a freelance journalist in the San Diego area.

**References**

Setting Goals and Managing Expectations for Chronic Illness

These guidelines are intended to help patients reach their goals without disappointing expectations.

By Surayyah Morris
**CHRONIC ILLNESS IS** like tug-of-war, walking a tightrope blindfolded and treading water in the middle of the Atlantic during hurricane season. Every move you make may have a different result each time. Consistency is a luxury. Your body and mind are fragile, and you want to keep them in the best condition possible. The goal is to prevent a vicious cycle of taking two steps forward and 10 steps back. Sometimes, to your surprise, you'll take two steps forward and then sprint to the finish line unscathed.

Setting goals is a great way to manage daily activities that affect physical and mental health and life in general. When you have a chronic illness, having defined goals gives you something to work toward while allowing you to reflect on what does and doesn’t work for managing your condition. Following is some goal-setting guidance.

**Goals Should Be SMART**

A starting point for setting goals is to use the acronym SMART, which stands for specific, measurable, attainable, realistic and time-based.

*Specific:* If you can answer the five W’s (who, what, when, where, why), you’re off to a great start. Be as detailed as possible when outlining the plan you want to accomplish.

*Measurable:* This is where the “H” comes in. How much? How little? How do you know when you’ve reached the desired outcome? You’ll want a way to quantify your progress.

*Attainable:* In what ways will you be able to work toward this goal? Are there any tools or people to help you?

*Realistic:* Anything is possible, but is your goal really something you can accomplish with the resources available to you?

*Time-based:* What is a reasonable length of time to achieve your goal? Organize short-term and long-term goals into days, weeks and months if necessary.

**Goals Should Be Intentional**

Be sure to consider how you will accomplish your goals. For instance, if you want to show your doctor you are serious about adjusting your treatment, present him or her with new research data. If you want to hang out with friends more often, reach out to them first. If you want to decrease the amount of exposure to infections, be proactive in maintaining a clean and safe environment. Ensure you start with small goals, and work your way to more challenging ones. Also, consider starting with only one goal, because having too many easily becomes overwhelming.

**Tackling Expectations**

After you’ve developed your SMART goals, it’s time to manage your expectations. Setting expectations too high can lead to disappointment if the goals aren’t reached. On the other hand, setting expectations too low creates a negative mindset with hopes that the outcome is better than expected, leading to further disappointment if the outcome is unfavorable. Sometimes, the fear of exhaustion, pain and sickness prevents us from doing anything at all. Yet, even with a chronic illness, something is better than nothing. In either instance, it is important to keep things in perspective.

The following are a few tips to encourage good results when setting goals and managing expectations.

*Start low and go slow.* Moderation is key. Take baby steps. There is nothing worse than getting overexcited to do something and, soon after beginning, you crash. Ease into the activity you are working toward. If you need to get moving, start walking in five-minute increments to build up stamina. If gravity isn’t your friend, water aerobics is a wonderful alternative. Yoga is also an option that gives more energy than it takes. On good days, it is easy to feel on top of the world, leading to a day full of activity and tasks that aren’t part of your normal routine. You have to do everything you can while you’re feeling OK, right? Wrong! Be cautious with your physical activity so overexertion doesn’t land you in unfavorable pain or injury in the days to follow.

*Take notes.* Slowly increase the amount you do each day, and keep a mental note or journal of your activity and record the following: 1) activity, 2) length of time spent performing that activity and 3) how you feel before and after the activity. When you keep track of what you are doing and how you feel afterward, you can adjust accordingly for next time. If you feel better (or not worse) afterward and the next day, you
should continue at that pace and make small increases in activity each day or week until you feel like you’ve reached your goal. If you feel worse afterward, take a break from the activity until you recover, and then try again with a little less effort to avoid overexerting yourself. It also helps to jot down any specifics such as weather, medications taken or tools needed for relief during and after your activity. You may not even have to modify your activity. You can change your environment to make it more comfortable whether it’s moving from outdoor to indoor, taking breaks or going hands-free by using wireless devices. If you know your limitations, respect them. When in doubt, rest. You will save energy and reduce the physical and emotional stress of the crash-and-burn by listening to what your body and mind are asking of you.

Beyond the physical. Other ways to manage expectations extend beyond physical activity. These same concepts apply with learning, parenting and personal life. Learning issues such as trouble concentrating can be improved with brain games. Set a goal to play 15 minutes of brain games daily. If parenting is becoming a bit much, see if grandparents can take the kids every other weekend. In your personal life, let go of the need to always follow routines and check off long to-do lists. Consistency is great, but not if it isn’t keeping you mentally intact. Create and follow your routine the best you can, but if you are unable to follow it exactly, do not be discouraged. Find a way to adapt to the change that has occurred or move on to something else, expecting that you will still reach the desired outcome, just a little more slowly. Rest if you need it. For your mental and emotional health, take a day to dump your brain of all things stressful and focus on yourself. Do not clean, work or worry about anything that doesn’t make you happy and relaxed. Mental health days are good for clarity and allow you to reset from the chaos of life.

What to Expect
Managing expectations with a chronic illness is as easy as riding that indoor roller coaster when it’s really dark. You have no idea where you are in space, you don’t know what drop or turn is coming next and you don’t know how long you have until the end. It can be frustrating when things don’t happen the way you expected, or better yet, the way they were supposed to. Expectations shift based on many factors that you typically don’t have control over. Some may find it easier not to have any expectations at all. Not having expectations relieves you of disappointment (and may save you a conniption fit or two). But, realistically, it’s kind of difficult not to presume, assume or suppose, especially when it comes to your health. That being said, here are a few times when having defined expectations is absolutely necessary:

1) Setting goals. You should always have at least this one expectation when setting goals: Expect to reach your goals and/or learn from the process. Be SMART and have perseverance.

2) Doctor appointments. You should attend with the expectation that you will leave with answers, whether or not they are the answers you want. Expect your doctor to refer you to someone who can help if he or she is unable to do so. Have a checklist of things you need to discuss at each appointment. Place the most important and time-sensitive requests at the top of the list to ensure those things are completed before moving on to anything else, even if it means not addressing the less-important items on your list.

3) Expect tomorrow. You should always expect to see the next day. No, tomorrow is not promised, but you need something to look forward to. Remain positive given your situation, knowing that you have something to live for. Expect that tomorrow will be another chance to accomplish your goals and make the progress you may not have made today. Tomorrow is a new opportunity to experience an amazing life despite your illness.

Making Health Decisions
Expect there to be a reaction for every action and a consequence for every decision (good or bad). Proactively manage your expectations in order to make responsible decisions when it comes to your health. Do you remember being taught to think before you speak? Along with watching your words, you need to watch your actions. Think before you do. Assess how your activity or action you plan to take
will affect how you feel at three very important times: 1) immediately, 2) at the end of the day and 3) the following day. What you do now will affect you later. The goal is to have a positive effect. For instance, let’s say you need to try something new and rejuvenating to clear your mind. For some, an hour of yoga may provide this rejuvenating effect. For others, a successful hike to the mountaintop is just as revitalizing. It can be frustrating to not always be able to do what you want, and that is OK. Find something you enjoy and are able to do with success, and keep doing it to provide a sense of independence. Remember to slowly increase and track your progress.

This positive cause-and-effect mindset is also relevant when taking care of business. Don’t expect the doctor’s office to always follow up with you, but be grateful if they do. Preparing ahead of time will relieve you of troubles on the clerical side of things. Set reminders to refill medications routinely (every 30 days, 90 days, etc.). The effect is you won’t run out of medication unexpectedly. If there is an inventory issue or insurance problem, you will know early, giving you time to rectify the issue before you need more medicine. Schedule follow-up doctor appointments as far out as possible during your first visit. The effect is you won’t be scrambling your schedule to fit in untimely slots at the last minute. You may always change the dates later if needed.

**Proactively manage your expectations in order to make responsible decisions when it comes to your health.**

**Communication**

Being transparent is the easiest way to combat misguided expectations when you have a chronic illness. If your superpower isn’t mind reading, then you are better off clearly expressing your ideas, concerns and feelings through effective communication. Ask questions to gain a better understanding or to clarify discrepancies. Be comfortable with sharing your expectations for how you plan to move forward with your treatments, and be open to all feedback. Never feel obligated to leave anything up to chance. Avoid expecting people to tell you everything you need to know; it usually isn’t an intentional omission of detail. Effective communication maintains clarity when your health is complicated and relieves assumptions about how you are feeling. It makes caring for one another easy and effortless.

**Count It All as Progress**

Set some goals, and have a great time working toward them. Taking a few steps back is never defeat; it is still progress. As long as you learn from the setback, you are doing something right. Keep your expectations balanced, and enjoy the process!

SURAYYAH MORRIS, PharmD, is an IG patient from Central Florida. As a medication therapy management and pain management specialty pharmacist, she enjoys supporting patients with chronic pain and chronic conditions to help find balance and improve quality of life.
Finding Support with Chronic Illness

In addition to family and friends, patients can find support to help them deal with their illnesses from a variety of sources, including groups, providers and therapists.

By Cynthia Perry

**PATIENTS WITH CHRONIC** illnesses experience many emotions as they journey from diagnosis to finding specialists and choosing treatments to manage their symptoms, all while navigating the U.S. healthcare system. Oftentimes, this journey takes twists and turns if their conditions progress and additional diagnoses are made. As a result, patients often experience a variety of emotions such as anxiety, depression and fear, and many must adjust their work, goals and lives to accommodate very real limitations imposed by their illnesses.

But, finding support can help. A study by Concordia University that asked, “Do sick people get lonely?” revealed they often do as they get older, whether or not they are in a long-term relationship. “The quality of our social ties plays a role when it comes to coping with the effects of serious disease in later life. And just having a partner around may not be enough,” says Meaghan Barlow, PhD, the study’s first author. “Putting a halt to socializing only contributes to a downward spiral. The fact that loneliness can lead to further complications means that measures can be taken to prevent the effects from looping back around. Finding different ways to connect with other people also means you are less likely to blame yourself for being sick, and you can’t count on a partner to fill that gap.”

Further evidence of the importance of social support comes from a review of papers published in *Chronic Illness* that found...
social networks, including friends and family, have a positive impact on patients’ long-term coping with chronic illness. Social networks can help ease burdens and shape how patients view themselves and their illness.²

Fortunately, patients can look to a variety of sources for support along their journey in addition to family and friends. Support groups and groups focused around hobbies or interests can provide social and emotional support. Organized exercise groups appropriate for patients’ medical needs can also provide a social outlet. And, patients can look to healthcare providers and trained therapists to provide important community resources.

Family

Family can be a wonderful source of support and encouragement. They are a logical first place to turn since they love the patient and want what’s best for him or her. Family members can attend appointments, be medical advocates, ask questions of providers, suggest different ways of looking at things and be a shoulder to lean on.

Although partners and other family members may worry about what the future will hold for the patient, and how it may affect their lives together, they can learn to cope as a couple and family. This is especially true since chronic illness is an experience of continual unpredictability, with good days and bad days or good months and bad months. During rough patches, the healthy partner and other family members can be called on to add the patient’s chores to their own. And, while this can add new stresses to a partnership and family unit, the following suggestions can help the family grow closer rather than apart:³

- **Acknowledge grief together.** Each partner will be affected differently by the illness, and each partner’s feelings are valid. Open and honest communication about these feelings is key to mutual understanding and growth.
- **Solve problems together.** Chronic illness can bring physical, emotional and financial burdens to a couple. Sometimes patients look well even when they aren’t, which can create misunderstanding and miscommunication in relationships. These problems can be

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approached as shared issues rather than something one or the other partner needs to solve on their own.

- **Appreciate the new normal.** As some activities and routines change out of necessity, the door can open to new ways of doing things as a couple. Even extended family can help the patient cope and adapt to his or her new normal. Family members can work together to monitor symptoms, identify obstacles to self-care and help the patient stick to medication, dietary and lifestyle regimens.

Friends

Friends can be another excellent source of support. Some friends know just what to do and say and how to help. But, other friends may feel helpless and, not knowing what to say or do, may do nothing at all. If the patient tells friends exactly how they can help, it can ease anxieties for both parties. For instance, one friend could be asked to drive the patient to appointments, one might be asked to make a meal, another to run an errand, and perhaps another to entertain the patient’s children when he or she isn’t feeling well. Or the patient might just want someone to come and keep him or her company or find ways to help him or her laugh at the situation.

Also, group emails, a blog or a trusted friend can be a good way for the patient to keep family and friends apprised of their situation. This way everyone can feel informed without putting too much burden on the patient.

Community Groups

Churches and other community groups can also provide support. These groups may be able to provide rides to appointments, meals and childcare during acute phases of the patient’s illness.

Organized exercise groups, with doctors’ approval, can provide social outlets, as well as stress relief and overall health benefits.

If the patient retires early due to his or her medical condition, “active adult” groups could provide socialization and fill some of the time that used to be devoted to a career. These groups engage in a wide variety of activities such as travel, lectures, exercise, arts, card and board games, and attending concerts and shows. Although normally available to people “50 and better,” some groups will make exceptions for membership.

Support Groups

Support groups specific to patients’ chronic conditions can be another tremendous resource. These groups can allow patients to share their personal experiences and hear from others who have been through similar events, helping them cope with their diagnosis and fight feelings of isolation. Patients can learn about community and other resources that might be available to them, and even learn about new technologies and treatments for their condition.

Patients may even develop friendships with others in a support group. These new connections will be built on a unique understanding of what each is going through, and a unique ability to offer perspective and support.

Healthcare Providers

Patients shouldn’t discount the assistance they can get from healthcare providers. Doctors and other healthcare providers can answer patients’ questions about their condition and the expected course it will take. They can educate family members about patients’ healthcare needs, discuss treatment options and develop a treatment plan in conjunction with patients and their families’
wishes. Having a plan in place may help to decrease the entire family’s concerns.

Providers can also inform patients about how they can best care for themselves. They can also remove obstacles to treatment, insurance, disability coverage and other frustrations patients may encounter. Lastly, they can refer patients to community resources, including disease management programs, case managers and clinical trials.

Trained Therapists

In some cases, trained therapists can aid patients in dealing with the changes in health, life goals, activities and relationships. Therapists can guide patients as they find new ways of viewing their circumstances and deal with coping while so many aspects of their lives change at once.

Therapists can also help patients decide how to handle relationships with their healthcare providers. For instance, if providers don’t agree on a unified treatment plan, a therapist can help the patient decide how he or she wants to proceed. And, if a member of a patient’s team isn’t a good fit, a therapist can help that patient find a new provider, thoughtfully determining the characteristics a patient might want to look for in a new provider.

Support Is Available

Patients with chronic illness have many people and groups they can rely on for support throughout their journey. Making specific requests for support can let people know how they can help. Spreading requests for support for their needs across multiple people — family, friends and professionals — can strengthen all of the relationships in patients’ lives.

Changes in relationships and friendships may happen, and when they do, patients should show compassion and understanding. Avenues for starting new activities and building new relationships exist, and patients can explore these to have rich and rewarding lives in spite of their medical conditions.

CYNTHIA PERRY worked in the medical device field for eight years, interviewing doctors and conducting market research and strategic planning. She now writes articles and teaches classes focused on healthcare. Cynthia has been diagnosed with multiple chronic conditions and is a breast cancer survivor.

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Profile: Carl Schlacht

By Trudie Mitschang

AS A RETIRED professional motorcycle racer turned insurance agent and entrepreneur, Carl Schlacht is a prime example of someone who refuses to let chronic illness hold him back. The 35-year-old Cleveland, Ohio, resident was diagnosed with X-linked agammaglobulinemia (XLA) as an infant, but he has gone on to defy the odds by pursuing his dream to compete in extreme sports.

Trudie: Tell us about your diagnosis.
Carl: My journey began at 1 year of age. I was at my babysitter’s house when I reached up onto the coffee table and spilled hot tea on myself. I ended up in the hospital with a third-degree burn. While I was in the hospital, I acquired a severe infection and my physician ran some tests and diagnosed me right away with XLA, a rare primary immunodeficiency. We learned XLA is a condition that affects the immune system and occurs almost exclusively in males. People with XLA have very few B cells, which are specialized white blood cells that help protect the body against infection.

Trudie: How did your family educate themselves about this rare disease?
Carl: Since I was diagnosed so young, we relied on my physician and immunologist. These days, it is so much different with all of the great online resources.

Trudie: What was life like for you growing up?
Carl: As a young active kid I loved playing outside with my friends. The last thing I wanted to do was sit in the hospital for hours after school or on a weekend getting infusions, but I had no choice. Otherwise, I lived a normal life, going to school and catching a cold here and there. At an early age, I decided I wasn’t going to let anything get in the way of realizing my dreams.

Trudie: How did you get interested in racing motorcycles?
Carl: My dad was into cars, and my parents encouraged my interest in racing. When I was 3 years old, they bought me a four-wheeler. I started riding in the backyard and, slowly, the track got bigger and more challenging. A couple years later, I got my first dirt bike and started racing around the country as an amateur. Every day after school when other kids were playing video games or watching TV, I would come home and practice riding to be ready for the next race. It kept me out of trouble, and I loved it. When I was on that bike, nothing else mattered. I wasn’t a kid with a serious immune disorder who had to have infusions. I was free and happy. Nothing could stop me. I felt like I was a healthy, normal child most of the time.

Trudie: Were you or your parents ever concerned about you pursuing a high-risk career given your diagnosis?
Carl: When I was a kid, my parents would make sure I had the right protective gear and got the right coaching to make sure I was safe and could excel in the sport. I did have injuries growing up and some surgeries, but I always stayed on top of my infusions and
Carl: I was injured in 2013 and was going to come back in the 2015 season, but I decided to retire and just do it for fun while I still can. I have friends who are paralyzed and even worse — some passed away from injury. I had a career in insurance lined up for several years with a friend’s company, so I was just waiting for the right time in my life. I am also a filmmaker, and I have won several awards for some of them at film festivals. I continue to make films, and I am getting back into racing in 2020 — just not on bikes. I’m transitioning to rally car racing. I am very excited about this!

Trudie: What are your goals now?
Carl: My goals for the future are to have a family, make movies and win rally car races around the world, along with sharing my story and helping others follow their dreams.

Trudie: Have you performed any patient advocacy work with the Immune Deficiency Foundation (IDF) or other organizations?
Carl: I attend many IDF programs, as well as do patient advocacy for CSL Behring.

Trudie: As you look back on your life so far, what are you most proud of?
Carl: I am so proud I have been able to accomplish my goals and continue to reach new goals that allow me to share my story with others. I enjoy giving people hope to know they can follow their dreams and not let anything hold them back. I was 3 years old when I first dreamed of racing bikes. Today, every time I ride, I still feel the same way I did when I was a kid riding my first dirt bike. Everything else drops away, and nothing can stop me. With determination and support from my family and my doctors, I’ve been able to achieve my goals. Whatever your dreams may be, you don’t have to let an immune deficiency keep you from realizing them.

My goals for the future are to have a family, make movies and win rally car races around the world, along with sharing my story and helping others follow their dreams.
The joke was on me.

"Whitney, you should be in the Guinness Book of World Records for having the most warts," the junior high boy snickered as if he just spouted a one-liner to rival a stand-up comedian.

I gasped as I felt heat rush to my face. "Don’t cry, don’t cry," I told myself, praying to God I wouldn’t disappear into a puddle of tears. I always tried to hide my overabundance of warts, compliments of my rare immune disease, but now those deformities were exposed for the entire world to see.

My friend threw her arm around my shoulders and spat the angry, sharp words I couldn’t utter at that moment. "How could you hurt her feelings like that!? She can’t help she has warts!"

"Sticks and stones may break my bones, but words can never hurt me…" Wrong! What a crock!

At that moment, the questions my chronic illness raised, which I had managed to bury deep within, came knocking on my heart like an unwanted houseguest.

Now, you may be thinking, “All right, she’s going to answer all of my questions!” Unfortunately, the answers aren’t cookie cutter, and all the questions I had growing up might not be the same as yours. But, I hope what I learned with each passing year will help you search for the balm you need to heal.

Question 1: Do people think my deformities are gross? Yes, some people think my warts are repulsive. The sad truth is “different” and “unusual” make the world uncomfortable. But I’ve come to see I can’t control others’ reactions to me, even if their words cut deeper than a two-edged sword. On the other hand, my friends who really know me — warts and all (come on, I still have a sense of humor) — those people see the real Whitney. They understand warts are only an extension of my disease; they don’t define who I am.

Question 2: Will a guy ever find me attractive? Whew, this is such a tough one. It’s a question I still struggle with considering I’m not married or in a relationship right now.

The heart-wrenching reality is warts aren’t “beauty marks” that most guys want in their “ideal girl.” After much soul-searching over the years, which I wish took place on a tropical island like it does in the movies, here’s my conclusion: The right guy will find me beautiful. Wow, these words sound so cliché after writing them, but I believe them. One day, when the time is right, the guy will adore all of me. The unwanted blemishes my chronic illness causes won’t disgust him, but he’ll see them as uniquely beautiful attributes that show my strength and perseverance.

Question 3: Do people pity me? Ouch. Pretty tough question, and the answer is difficult to swallow. Yes, people pitied me growing up, and they will continue to do so. It’s just a vicious cycle of “dirty laundry” that will never end. To these individuals, I wasn’t in the top percentile on their “growth chart of success.” Here’s what I learned: Their tunnel vision of my deformities and limitations can never erase the “joy” and “can-dos” I have experienced. I couldn’t allow their pity to transfer to my personality because self-pity would only “stunt my growth.” Especially since I know what I am capable of and what I deserve.

Notice the common thread in the answers to each of these questions? They are messy, and it took time for my internal bruises to heal. What I’m saying is you’re still adjusting to what your disease means. The hard-knock life reality is you are not “bubble-wrapped” against human error or negativity, and this can create confusion when sorting through your feelings and tears. But, there’s a key to unlocking this heavy assignment: The secret is not allowing others’ words to define you. You decide who you want to be and how you want your chronic illness to shape your life. The more you embrace this philosophy, you’ll notice something beautiful: When hurtful words knock you down, you’ll have the strength to keep getting back up.

Whitney L. Ward was not only the first person in the world diagnosed with MAGIS syndrome, she had the honor of naming the new primary immune deficiency. MAGIS means “more” in Latin, and Whitney hopes to instill in her readers the message they are more than their disease. Find out more about Whitney’s journey at www.whitneylaneward.com.
Careers for Passionate PI Patients

By Ilana Jacqueline

IF YOU’VE picked up this magazine, chances are your life has been impacted by a primary immune deficiency disease (PI) or another disease requiring treatment with intravenous immune globulin (IVIG). As the use for IVIG grows, so does the need for patients with experience to take on roles in the industry — not just to advocate, but to make, market and distribute the medication that helps keep us alive. Whether you’re a 20-something looking to find your career path or the parent of a child with a PI, knowing you can make a real difference for other patients can bring inspiration and hope. Here’s a breakdown of some careers that could use real patients, real people and real passion to help our community thrive.

Scientists and researchers. As we experience a drought of the most essential biologic needed to treat PIs, scientists and researchers are needed more than ever before to find new ways of understanding and treating our disease. There is a wealth of opportunity open for science, technology, engineering and math majors looking to get involved in the creation and improvement of new treatments. What if you’re the key to finding a cure?

Media and marketing. If chemotherapy were in short supply, that news would be splashed across every major newspaper in the world. Quite the opposite, coverage about our IVIG shortage hasn’t even made the evening news. We need passionate reporters, storytellers and inquisitive writers and interviewers to ask the hard questions to give our community a voice in mainstream media. Internally, marketing companies for plasma banks and pharmaceutical companies need influencers who can speak to the importance of finding great candidates to get the job done. If you’ve got great communication skills, we need you now more than ever.

Doctors and nurses. If you’ve ever seen a lackluster immunologist (and we know you have), you know how life-changing it can be to meet a doctor who cares and understands the realities of your condition. Doctors and nurses who live with PIs can give new insights into how to make treatment plans more livable. They can identify with the hardships patients and their families face on a daily basis, and they can pave the way for safer hospital and doctor office conditions for all patients.

Social workers and psychologists. I’ve said it before in this column: We all need therapy to cope with the stress of chronic illness. It can be hard to find psychologists and social workers with personal experience with these diseases and who can give solution-based advice. A career in social work can be highly rewarding, and virtual therapists who can work with patients from their hospital rooms or sickbeds are in demand.

Quality assurance and regulatory affairs. Quality assurance is essential for ensuring IVIG manufacturing documentation meets U.S. Food and Drug Administration standards. Regulatory affairs representatives make sure all drugs and tests produced by a company meet regulatory standards. This work is vital to make certain every lifesaving plasma product is safe and effective for patients in need. To be a part of the quality assessment and regulatory teams, you need strong verbal and writing skills with especially strong editing abilities to ensure all documentation is clear and concise. This work helps company researchers and scientists keep their processes consistent.

While your disease doesn’t have to be your life, it can inspire your career, which can impact and improve the lives of patients for years to come. There are so many ways to be a part of the solution, and you have the edge to break into an industry that’s looking for the best and brightest. As long as patients continue to be born with PIs, we’re recruiting.

ILANA JACQUELINE is a dysautonomia and primary immune deficiency disease patient from South Florida. She’s been writing professionally since 2004 on everything from health and wellness to celebrities and beauty. Her blog www.letsfeelbetter.com is both a personal collection of anecdotes about life with chronic illness, as well as a resource for patients of all ages.
IN RECENT years, numerous global outbreaks of diseases previously declared eradicated in the United States have occurred. During the first half of 2019, 364,808 measles cases were reported to the World Health Organization from 182 countries, which is more worldwide measles cases than in any year since 2006.1 In the U.S., 1,249 measles cases were reported from Jan. 1 through Oct. 4, 2019 — the greatest number of measles cases in the country since 1992. Most of those cases were associated with large outbreaks in New York City and some other cities in the state, mostly involving unvaccinated children in Orthodox Jewish communities, whose origins can be traced to unvaccinated travelers who brought measles to the U.S. from other countries at the beginning of October 2018.2 Thankfully, with the end of the New York measles outbreak, the U.S. has kept its eradicated status. According to the U.S. Department of Health and Human Services, “Measles elimination status is lost immediately if a chain of transmission in a given outbreak is sustained for more than 12 months.”3

Mumps has been circulating in increasing numbers as well. From Jan. 1 to Oct. 11, 2019, 48 states reported mumps infections in 2,618 individuals. According to the Centers for Disease Control and Prevention, “Before the U.S. mumps vaccination program started in 1967, about 186,000 cases were reported each year, but the actual number of cases was likely much higher due to underreporting.” Since the introduction of the two-dose measles-mumps-rubella (MMR) vaccine in 1989, mumps cases in the U.S. have decreased by more than 99 percent. Now, only a few hundred cases are reported most years. However, cases started increasing each year since 2006, and outbreaks have been occurring about every five years.3

In the U.S., mumps outbreaks can still strike even in people who have previously had one or two doses of the MMR vaccine, particularly in close-contact settings such as households, schools, universities, athletics teams and facilities, church groups, workplaces, and large parties and events. High vaccination coverage, which leads to what is known as “herd immunity” helps limit the size, duration and spread of mumps outbreaks, as well as outbreaks of many other contagious diseases.3

Disease Outbreaks and the Primary Immunodeficiency Disease (PI) Community

These disease outbreaks are frightening developments for families of PI children. I am a member of a Facebook Group comprised of X-linked agammaglobulinemia (XLA, a type of PI) patients and their caregivers, and in this group, the topic of disease outbreaks comes up several times a year. If there is an outbreak of measles or whooping cough (pertussis) in close proximity to a child who suffers from PI, parents often ask: “Do my child’s immune globulin (IG) infusions protect him from measles?” The same question is asked about any number of communicable childhood diseases such as chickenpox, influenza or mumps. It’s a very natural question to ask if your child comes in contact with one of these diseases when he or she doesn’t have the ability to mount an antibody response against it or get vaccinated to protect against it.

Responses to this question, though, are mixed. Some parents and patients say, according to their doctor, IG infusions provide enough “passive immunity” to keep patients safe and protected if they were to come in contact with the viruses. Unlike active, or natural, immunity that occurs when exposure to a disease organism (either the disease...
itself or a vaccine for that disease) triggers the immune system to produce antibodies to that disease, passive immunity is achieved when antibodies are given to a person (such as through IG infusions), rather than the person’s own immune system producing them. This is how members of the PI community are protected from diseases such as measles, mumps or pertussis.

While passive immunity is theoretically provided by IG infusions, several members of the XLA community on Facebook, usually XLA patients, will mention they’ve had measles or chickenpox before (some multiple times) even while receiving infusions. Since IG infusions are the only options PI patients have to provide protection against these pathogens, patients and parents must be sure to have IgG levels checked several times a year to ensure they are at the level necessary to provide the most complete protection possible.

The Importance of Herd Immunity

This is why protection offered by herd immunity is so important. The fewer people who become infected with a disease, the smaller the chances are of contracting it. As defined by the University of Minnesota, herd immunity is “the protection that occurs when a high proportion of people are vaccinated against a specific virus or pathogen.”

To attain herd immunity and protect an entire community from a disease, a very high percentage of people in that community need to be vaccinated, known as the “threshold.” To attain herd immunity and protect an entire community from a disease, a very high percentage of people in that community need to be vaccinated, known as the “threshold.” To attain herd immunity and protect an entire community from a disease, a very high percentage of people in that community need to be vaccinated, known as the “threshold.” To attain herd immunity and protect an entire community from a disease, a very high percentage of people in that community need to be vaccinated, known as the “threshold.” To attain herd immunity and protect an entire community from a disease, a very high percentage of people in that community need to be vaccinated, known as the “threshold.”

According to Michael Brady, MD, associate medical director at Nationwide Children’s Hospital in Columbus, Ohio, “The more contagious a disease is, the higher percentage you need.” For example, to establish herd immunity for measles, 93 percent to 95 percent of people in a community have to be vaccinated. That means for every 100 people, about 95 need to get vaccinated to prevent the disease.6

The recent outbreaks of measles and mumps have occurred in areas where herd immunity has been compromised because vaccination numbers have dropped below the threshold necessary to provide protection. Outbreaks occur when germs spread rapidly from person to person, infecting many within a community. But if enough people are vaccinated against a disease, germs can’t spread and the entire community may be spared from an outbreak.7 This includes those within the community who cannot get vaccinated due to underlying medical conditions such as PI. And, even if an individual does happen to contract the disease, it likely won’t spread if enough people surrounding this individual are vaccinated.

Boosting Herd Immunity

So, how can we boost herd immunity? With vaccination numbers dropping in recent years, parents of PI patients might find themselves discouraged. But, could educating the public about the importance of herd immunity raise the percentage of those who receive vaccines? Possibly.

In 2016, two former University of Minnesota students conducted a study to determine whether people consider the benefits to their community (such as herd immunity) when choosing to get a flu shot, as well as whether educating people about herd immunity would make them more likely to get vaccinated. They found that one-third of people had no idea their decision to get the flu vaccine could benefit others, and those individuals were also the least likely to get the flu vaccine. After educating this subgroup about the benefits of high vaccination coverage in a community, their willingness to get vaccinated increased by 7.3 percent.8

While it may be surprising to learn there are still people who don’t understand the benefits of herd immunity, it only highlights the need for PI patients, parents of PI children and others to spread the word about its importance. The University of Minnesota students recommend doctors, nurses and pharmacists who administer vaccinations emphasize to their patients both the personal benefits of vaccination in protecting against disease and the community benefits of herd immunity in preventing outbreaks.9 If we take the time to educate those in our small spheres of influence, we can reach a wide range of people, leading to a safer community for us all.

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Personalizing the Infusion Experience

By Heather Bremner Claverie

HOME, HOSPITAL, outpatient clinic or doctor’s office? Today, patients receiving immune globulin (IG) infusions have a lot more choices, which is an improvement over the past when the only option was to receive infusions in a hospital or clinic setting. This changed in the 1980s when insurance companies began eyeing potential cost-cutting strategies, opening the doors to home-based infusions.

Convenience with Lower Costs

Driven by a desire to avoid the risk of healthcare-associated infections and to take advantage of the comfort and convenience of home, more patients are opting for home-based infusions. In addition, costs may be cut significantly with home-based infusions due to lower contracted reimbursement and fewer ancillary charges, making it an enticing option for insurance companies.

Safety in the Infusion Setting

Infusions can be safely administered in the home setting. However, being aware of different side effect profiles for subcutaneous IG (SCIG) and intravenous IG (IVIG) is important. Typically, SCIG causes fewer systemic side effects than IVIG.

SCIG patients are trained to become independent with administration, and once they have mastered the process, they can continue to self-infuse unsupervised.

For patients receiving IVIG, the standard of care is to have a nurse administer each dose of IVIG and remain in the patient’s home for the duration of the infusion.

Still, for some patients, a hospital or clinical setting is not simply a better option, it’s the safest one. Hospital or clinic administration may be necessary for patients who have a history of significant reactions with IVIG doses. And, infusing in a hospital or clinic gives doctors and nurses the opportunity to interact with their patients more often, while also supervising and monitoring their health and response to treatment.

The Medicare Hurdle

But, reimbursement can pose challenges when it comes to IVIG vs. SCIG. Medicare Part B provides limited coverage for IVIG and SCIG in the home setting. While Part B covers many different types of conditions in the physician office or hospital infusion suite, coverage at home is limited to 24 primary immune deficiency diagnoses under the IVIG benefit, and there is no additional payment for a pump or supplies.

On the other hand, Medicare does provide coverage for the cost of the mechanical pump and associated supplies needed for SCIG therapy under the durable medical equipment benefit. Medicare also covers nursing services for SCIG patients with the 24 Part B-covered diagnoses while they are learning to become independent. Patients with diseases other than the 24 PI diagnoses may receive coverage under Medicare Part D; however, unless the patient has a Medicare Advantage plan, supplies and nursing services are not covered, which may prompt patients to receive therapy in hospitals or outpatient centers.

The Right Choice

Weighing the pros and cons of infusing in a doctor’s office, clinic, hospital or home isn’t as simple as deciding which setting is preferred. Cost, flexibility and safety are all factors that should be considered by patients and their doctors before settling on the right infusion environment.

HEATHER BREMNER CLAVERIE is a contributing writer for IG Living magazine.
Uncomplicated Healthcare

The IDF ePHR is an electronic personal health record developed by the Immune Deficiency Foundation specifically for patients with a primary immunodeficiency disease. The system gives patients the power to track, store and share health information — all in one secure online program. Free; www.idfephr.org

Infuse Intelligence

The Ivenix Infusion System’s smart pump uses advanced technology to enhance patient safety and improve infusion delivery. Its smartphone-like design encourages programming accuracy, while its automatic drug library and real-time dose guidance improves safety and drug compliance. Ivenix customers can take advantage of the included management system — a set of scalable tools, applications, analytics and dashboards that help healthcare providers manage infusion pumps and clinical information systems. Pricing varies; www.ivenix.com

Shopping Guide to Infusion Environments

Clean the Air

Maintaining a clean and healthy home is always important, but it’s even more significant when that environment is the site of infusions. An air filter such as the Blueair Blue Pure 211+ can help filter out any mold spores, dust, pollen or viruses hanging out in the home, making both the air and the infusion environment safer. $282.49; Amazon.com

Just Relax

A comfy spot is a necessity when sitting for long periods during infusions, but any old chair won’t suffice. Comfort, safety, convenience and cleanliness are all factors that the La Z Boy Tranquility Mobile Medical Recliner addresses. With easy-to-clean vinyl and a locking backrest option, patients can infuse in comfort. In addition, optional features such as side trays, IV poles, foot trays and seat heaters are available. $1,586; www.medicalresources.com/la-z-boy-leda-mobile-medical-recliner.html

Soften Up

All that hand washing can really wreak havoc on skin. 3M Cavilon Moisturizing Hand Lotion is a great solution for individuals who are frequently washing and sanitizing their hands. The lotion, which is compatible with chlorhexidine gluconate, will soothe and soften skin without breaking down latex gloves. It is fragrance free and hypoallergenic. $15.10; Amazon.com

Hug It Out

Weighted blankets are all the rage now for individuals dealing with everything from anxiety to insomnia. For infusion patients who may become anxious or nervous during their treatments or who have sleeping issues, weighted blankets may be a great option. Choose a blanket that’s between 7 percent and 12 percent of your body weight for a feeling that proponents of this product say is akin to the feeling of a gentle hug. $68.90 and up; Amazon.com
Maximize Your Medicare: 2020-2021 Edition: Qualify for Benefits, Protect Your Health, and Minimize Your Costs
Author: Jae W. Oh
Publisher: Allworth

This informative guide by nationally recognized expert Jae W. Oh helps readers understand how and what to choose when deciding on Medicare options. This book shows readers how to enroll in Medicare and avoid never-ending penalties; compare Medigap vs. Medicare Advantage; discern the differences between Parts A, B, and D; increase benefits every year; avoid costly errors; deal with special circumstances; and get the most from the plan. This resource is intended for individuals aged 65 or older, as well as for their families and care coordinators.

End Chronic Disease: The Healing Power of Beliefs, Behaviors, and Bacteria
Author: Kathleen DiChiara
Publisher: Hay House Inc.

In her book, nutrition educator, researcher and health advocate Kathleen DiChiara explains what she believes conditions the body to overcome illness. She shares her passion for functional medicine, microbiology and growth mind-set, and helps readers discover the key strategies that impact the three driving forces for optimal health: beliefs, behavior and bacteria. In this book, readers will find a health-conscious and practical guide to build physical health and immunity.

The Disease Delusion: Conquering the Causes of Chronic Illness for a Healthier, Longer, and Happier Life
Author: Jeffrey Bland, PhD
Publisher: Harper Wave

For decades, Jeffrey Bland, PhD, has been on the cutting edge of functional medicine, which seeks to pinpoint and prevent the cause of illness, rather than treat its symptoms. In The Disease Delusion, Dr. Bland explains what functional medicine is and what it can do for individuals. According to him, while advances in modern science have nearly doubled lifespans in only four generations, people’s quality of life has not reached its full potential. He outlines the reasons people suffer chronic diseases from asthma and diabetes to obesity, arthritis and cancer to a host of other ailments, and offers achievable, science-based solutions that can alleviate these common conditions and offers a roadmap for a lifetime of wellness.

Sick of Being Sick: The Woman’s Holistic Guide to Conquering Chronic Illness
Author: Brenda Walding, DPT, FDN-P
Publisher: Morgan James Publishing

Sick of Being Sick shows women how to move beyond the prison of chronic illness and persistence of health challenges. Dr. Brenda Walding reveals the essential elements to healing, as well as powerful tools, tips, concepts and daily practices essential for radiant health. She teaches women how to overcome overwhelm and fear to make decisions for their highest good, how toxic thoughts and poisonous practices are massively sabotaging their healing efforts, and much more. For the women who are ready to begin their journey to wellness, this book is their portal of transformation and opportunity to bring them back to their heart, to love themselves again and to experience wholeness.
Download the *IG Living* eBook today—now available for iPad, Nook and Kindle!

“You can lament what is lost to you, whether it’s opportunity, a person or your health, but clinging to anger is no way to experience life.” — Rebecca Zook in “Life Lessons,” excerpted from *Chronic Inspiration*.

Download a daily dose of inspiration with this heartfelt compilation of writings on life with chronic illness. From coping strategies and parenting tips to “from the trenches” advice on dealing with family and friends who simply don’t get it, these personal stories are sure to uplift, challenge and inspire. Honest and candid, *Chronic Inspiration: Heartfelt Perspectives on Life with Chronic Illness* gives voice to those who refuse to let their diagnosis define who they are or what they can accomplish.

“For the patient community, this was invaluable. When I downloaded it, I knew this would be something I would refer to over and over again.”

— Jenny Gardner

*Chronic Inspiration* can be purchased on iTunes, Amazon and Barnes and Noble.com
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