HEALTHCARE QUALITY
A Changing Era of Medicine

Tips for Navigating Healthcare’s New Terrain

How Patients Can Be Their Own Advocate

Immune Globulin Therapy During Pregnancy

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Flublok®
Influenza vaccine

Pure  Simple  Effective

ACIP recommended for ages 18-49
Also recommended for those with egg allergies

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To order Flublok, contact
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(800) 843-7477

Protein Sciences CORPORATION
Reimbursement Codes
CPT code: 90673
Q code: Q2033
Flublok (Influenza Vaccine)
Sterile Solution for Intramuscular Injection
Initial U.S. Approval: 2013

BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use Flublok safely and effectively. See full prescribing information for Flublok available at www.Flublok.com.

INDICATIONS AND USAGE
Flublok is a vaccine indicated for active immunization against disease caused by influenza virus subtypes A and type B contained in the vaccine. Flublok is approved for use in persons 18 through 49 years of age.

DOSAGE AND ADMINISTRATION
A single 0.5 mL dose for intramuscular injection.

DOSAGE FORMS AND STRENGTHS
A sterile solution for injection supplied in 0.5mL single dose vials.

CONTRAINDICATIONS
Severe allergic reaction (e.g., anaphylaxis) to any component of the vaccine.

WARNINGS AND PRECAUTIONS
If Guillain-Barré syndrome has occurred within 6 weeks of receipt of a prior influenza vaccine, the decision to give Flublok should be based on careful consideration of potential benefits and risks.

ADVERSE REACTIONS
In adults 18 through 49 years of age, the most common (≥10%) injection-site reaction was pain (≥37%); the most common (≥10%) solicited systemic adverse reactions were headache (≥15%), fatigue (≥15%) and myalgia (≥11%).

To report SUSPECTED ADVERSE REACTIONS, contact Protein Sciences Corporation at 1-888-855-7871 or VAERS at 1-800-822-7967 or www.vaers.hhs.gov.

USE IN SPECIFIC POPULATIONS
• Safety and effectiveness of Flublok have not been established in pregnant women, nursing mothers, children, or adults 50 years of age and older.
• A pregnancy registry is available for Flublok. Contact: Protein Sciences Corporation by calling 1-888-855-7871.

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www.Flublok.com
A New Way of Practicing Medicine
“There is good reason for patients to question whether the days of the kind and patient doctor can still be found.”

Tips for Navigating Healthcare’s New Terrain
“Having an understanding of what goes on behind the scenes, before and after the visit, goes a long way toward making clinic visits more satisfying.”

Patient Advocacy: How Patients Can Gain Control
“Patients need to get educated about their particular health concerns before entering their doctor’s office.”

Immune Globulin and Pregnancy
“Most physicians believe IG is safe during pregnancy, and that its benefits outweigh its risks.”

IG Chronicles: Needles & Spines
“In some ways, I feel like a fraud being here. I’ve been asked more than once what kind of cancer I have, and I actually feel bad explaining that I don’t have it.”

Connect with Other IG Living Readers through Monthly Teleconferences!

IGL’s Readers Group Teleconferences allow readers to connect with others to share their experiences living with chronic diseases. Here’s how you can participate:

- Email IG Living to be added to our email invitation list for the teleconferences.
- IG Living will send you invitations to let you know when the monthly, hosted, toll-free teleconferences will be held, as well as what topic relevant to the IG community will be discussed.
- The moderated, hour-long calls will be filled on a first-come, first-served basis and will be limited.

In addition to connecting with others, IG Living’s patient advocate can help you determine if there’s a patient organization support group in your area.

Sign up for the Teleconferences now by emailing akazemi@IGLiving.com or calling (800) 843-7477, ext. 1366.
Progress vs. Change

Consider the anonymous quote: “Everyone loves progress, but nobody likes change.” This is especially true when change is forced upon us and when it may affect us negatively. Right now, there is a lot of change occurring in the area of healthcare — some of which is apparent to patients, but a lot is happening behind the scenes, making itself apparent only in its effects. That’s what the main focus of this issue is about: how changes in healthcare may ultimately be affecting patients and how patients can best weather these changes.

Dr. Sue Romanick, a rheumatologist who specializes in autoimmune diseases, is no stranger to how these changes are affecting healthcare providers. In her article “A New Way of Practicing Medicine,” she explains how the increasing demands of electronic paperwork that must be submitted to insurance companies and third parties take physicians’ time away from “real doctoring.” She also shares how the administrative burden placed on physicians to obtain preauthorizations often inhibits doctors from ordering necessary tests and medications. But, her goal in writing the article is not to complain; she wants patients to understand why many of the changes taking place are affecting the quality of patient care. As Dr. Romanick so compassionately asks: “Surely, saving lives and limiting disability reflect the true quality of healthcare?”

So, what’s a patient to do? Carsten Schmiedl, manager of a small healthcare clinic, also discloses what’s going on behind the scenes in physicians’ offices. In his article “Tips for Navigating Healthcare’s New Terrain,” he, too, lends his perspective on the changing healthcare terrain and its effect on office visits for both physicians and patients. In addition, he provides some tips for getting the most out of these interactions.

IG Living’s patient advocate, Annaben Kazemi, goes a step further in her article “Patient Advocacy: How Patients Can Gain Control.” From seeking out knowledge to knowing their rights and obtaining assistance, there are a great number of ways patients can advocate for themselves. Kazemi outlines the steps patients can take when dealing with doctor visits, managing healthcare reimbursement and obtaining assistance in covering the cost of their care. Also included is a list of free advocacy services.

Whether we do or don’t support the changes taking place due to the Affordable Care Act, changes are underway, and many more are set to go into effect this year and beyond. The professed goal of these changes is to advance our healthcare system so that it ultimately provides a higher quality of care for patients. Nonetheless, it’s inevitable that all of us may experience some negative effects at some point. To weather these difficulties, we need to be aware of why these effects are occurring and arm ourselves with strategies for either adapting to or overcoming them.

I hope you gain insight from the information presented and enjoy the many other articles in this edition of IG Living.
I really appreciated Dr. Lamberts’ [article] “A Letter to Patients with Chronic Disease” in the August-September issue of IG Living. Until I read it, I never thought about my interactions with my family physician, neurologist, gastroenterologist, OB-Gyn and even my dentist, expecting them to understand my immune deficiency. I throw around terms such as CVID and IVIG without even thinking. I really should know better, having been a corporate writer for 20 years who fought the use of corporate jargon. Shame on me! Thanks so much for printing this eye-opening article, and to Dr. Lamberts for writing it.

— Gail Norris

IG Living Reaches Patients Across the Globe

Thank you for the opportunity to share information about primary immunodeficiency disease (PIDD) and rare illnesses with other people. Because of your magazine, I have become more skilled at dealing with my illness. I receive home healthcare, and I would like to read an overview of different kinds of subcutaneous therapies, as well as the infusion pumps and others’ experiences with these pumps. Because PIDD is a rare illness, we patients live far away from one another. Living in Norway, I need information, and thanks to Facebook and this magazine, I’m grateful for having friends from the U.S. and all over the world. In Norway, we do not have a magazine; we have a National Center for Rare Illnesses, but there are very few patients.

— Ida Wagner

Thank you for making the IG Living readers teleconference titled Insurance Denials 101: How to Fight Back possible. The information shared was very helpful, and Leslie Vaughan did an excellent job as presenter. I am grateful to you and to IG Living for providing this opportunity, and I want to thank you for all you do on behalf of IG patients!

— Don Riker

Thank you for the blog on starting a support group by Annaben Kazemi! Meeting others who understand what it’s like to live with a chronic illness is so important, and your recommendations are helpful. The Immune Deficiency Foundation (IDF) welcomes those looking to connect with others. We provide patients and family members living with primary immunodeficiency diseases (PIDDs) multiple opportunities to connect to others going through similar experiences, including sessions at our patient meetings, retreats and national conferences. In addition, we have IDF Get Connected Meetings, which are just for patients and family members and are held in local communities at a library, coffee shop, church or other community venue. Anyone interested in attending or organizing an IDF Get Connected Meeting can contact IDF for more information at (800) 296-4433 or idfmeetings@primaryimmune.org. To see upcoming Get Connected meetings and other events, visit primaryimmune.org/events-calendar.

— Kara Moran

I have been receiving intravenous immune globulin (IVIG) for a year and a half now for polymyositis. I read your magazine and look forward to each issue. I belong to many support groups on Facebook, and most will agree that, for the most part, once they figure out what works best for them (rate, brand, etc.), they are side-effect free. However, one month, out of nowhere, they’ll experience horrible side effects afterward even though they followed their usual regimen (extra hydration, pre-meds, rate of infusion, etc.). It has many of us wondering what changes. Is it possible to do an article on the safety of donors and the quality controls regarding various batches of IVIG? Thanks for taking the time to listen to my suggestion. I/we really appreciate all that your organization does for education, awareness and support.

— Shelly Stiller

Your feedback, opinions, suggestions and anything else you’d like to share are important! Email us at editor@IGLiving.com or visit www.IGLiving.com and go to the Be Heard/Feedback page to send your comments.
Did You Know

Ask the Experts

Reader: I’m planning a trip with my son who requires intravenous immune globulin (IVIG) infusions. I’d like to take the IV fluids and supplies on the airplane as carry-on luggage. Will I have any problems getting through security and taking them on the plane?

Annaben: The Air Carrier Access Act mandates that prescription items and devices needed to administer them such as syringes must be allowed in the cabin of an airplane, provided they fit into the overhead bin or under the seat. Furthermore, these items are not counted in the carry-on limit. Contact the airline directly to find out about their size limitations for carry-ons. Then, pack your supplies in an appropriately sized bag and label it “medical supplies.” Don’t pack any personal items in with the medical supplies. And, of course, take along your prescription or a physician’s note that states your son medically requires the IV fluids.

The Transportation Security Administration (TSA) allows medically necessary liquids and prescriptions to be carried through security checkpoints. While there is no limit to the amount you may bring, if you have more than 3 ounces, you must declare it to the TSA officer before you pass through security screening. This will require you to allow plenty of extra time for the security check. TSA will ask you to open the suitcase and remove the items so they can manually inspect them and, perhaps, swab them for explosive residue. When they are finished, they will let you repack the items yourself.

Reader: I tried subcutaneous immune globulin (SCIG) infusions several years ago, but because it was very painful, I resumed intravenous IG (IVIG) infusions. Now, I am reconsidering SCIG because my IVIG appointments are taking up to eight hours. Has the SCIG method become less painful?

Leslie: Most people tolerate SCIG fairly well and don’t experience a lot of pain. As the SCIG infusion method has become more familiar, we have learned a few tips to minimize the issue you experienced. There are three things that are most important when inserting the needle to minimize pain:

1. Insertion location and technique. It is important to find a location where there is enough tissue to avoid any pain. Thighs, belly and back of the arms are usually best. The rule of thumb is to use a place where you can “pinch an inch.” A nurse can show you the best way to insert the needle without a lot of pain.

2. Needle length. In the past few years, manufacturers of SCIG needle sets have recognized the need to make different needle lengths for different body types. It is important to choose the right needle length so the needle stops in the subcutaneous space and not in the outer layers of the skin or the muscle. If the needle is not in the right space, the IG solution itself can cause a lot of pain and stinging. Again, a nurse can help you with choosing the right needle length.

3. Dry insertion technique. The tip of the needle should be completely dry when it is inserted. For IV therapy, nurses are taught to prime the IG solution all the way through the tubing to avoid introducing any air into the bloodstream. When SCIG was introduced, the same method was followed, and the solution was primed through the tip of the needle. Unfortunately, with this method, all of the sensitive spots in the outer skin layer are exposed to the drug during the insertion of the needle, which can cause pain. Now, we teach people to prime to the end of the tubing, but stop before the solution gets to the needle.

Also, if the pain was caused just from the needle insertion itself, there are creams such as EMLA that you can use to numb the skin before the needle is inserted.

Annaben Kazemi is the patient advocate for IG Living magazine.

Leslie J. Vaughan, RPh, is senior vice president of clinical services at NuFACTOR Specialty Pharmacy.
THE PARENTS OF a 2-year-old boy who is brought in for evaluation due to chronic respiratory symptoms have been told by his physician that he has a virus. They are concerned because it seems that he always has a virus and is never free from symptoms. His physician has tried to reassure the parents that it is common for a toddler to have viral respiratory symptoms, especially due to his age, exposures in daycare, etc.

The question, however, is whether this boy’s illnesses are normal or whether an immunodeficiency should be suspected. The maternal protective antibody that passes through the placenta into the developing baby is generally gone between 3 months and 6 months of age. As a consequence, most infants do not begin experiencing respiratory illnesses until after 3 months or 4 months of age. Infants and young children are reported, on average, to experience about six respiratory infections per year. Nonetheless, it can still be normal for some to have up to 12 respiratory infections per year.

Generally, the respiratory infections are mild and last no more than a few days requiring only symptomatic treatment. And, importantly, there are typically long stretches of time between illnesses when the child is well. The exceptions to this are during the winter months when some illnesses may come in quick succession, creating longer periods of illness with less time between illnesses, and for those children who are in daycare. Viral illnesses tend to cluster more in the late fall, winter and early spring months, leaving summer months free from major viral respiratory infections. And, children in daycare may have more frequent illnesses than those in smaller or more limited-exposure settings. In general, despite the exceptions, by 2 years to 3 years of age, the frequency and severity of infections slows, and they become more of an issue in winter months. When assessing a patient for a suspected immunodeficiency, it is critical to consider the patient’s detailed history of the age of onset of illness, number and length of illnesses, the time of year they occur, their severity and whether there is a need for antibiotics.

In this case, the boy’s first viral respiratory infection began before 1 month of age, during the summer and before the infant had significant exposure to others. Further, he was ultimately treated with an antibiotic to resolve the initial illness, confusing the issue of whether this was truly a viral illness. While worse during his first two winters of life when there would appear to be a continuous respiratory illness present, he continued to have illnesses throughout the spring, summer and fall months. Especially during the winter months, multiple courses of antibiotics were prescribed. And, after two years, the illnesses were not decreasing in intensity or severity. Therefore, the features of this case are certainly compelling that this boy could be suffering from an immunodeficiency.

We will continue with the discussion of this case in the next issue. ■

TERRY 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.

Disclaimer: This case report is intended as an illustration for education purposes only. It does not necessarily represent an individual or precise information from patient files.
**Contest**

**Enter IG Living’s Fourth Annual Essay Contest!**

*IG Living* is hosting its fourth annual essay contest open to IG patients and their caregivers ages 18 and older. We are asking entrants to start their essay with the same phrase. To participate in the contest, begin your essay by completing this sentence: If I had a chance to live illness-free for 72 hours, I would...

Guidelines for essay submittal are as follows:

- Write no more than 600 words, and be sure it is typed and double-spaced.
- Include a title for your essay, and include the author’s name, complete address, email, phone number and word count.
- Submit your entry electronically as a Microsoft Word attachment to editor@IGLiving.com, or submit it by mail to: IG Living Essay Contest, 41093 County Center Drive, Temecula, CA 92591, Attention: Carla Schick.
- Mail your entry by June 1, 2014 (must be postmarked by that date).

*IG Living*’s judges will rate the entries on a scale of one to 10 on five criteria:

- Organization (the writing flows logically with clear structure)
- Mechanics (spelling, capitalization and punctuation are correct)
- Content (subject is discussed clearly, and the reader is left with a finished feeling)
- Creativity (content is compellingly interesting for our audience)
- Effectiveness (the whole entry is effective in its purpose for our audience)

Winners will be announced on July 1. The first-place winner will be awarded an iPad mini, and his or her essay will be published in *IG Living* magazine. Second- and third-place winners will be awarded a $50 gift card, and their essays will be published in an IG Living blog.

This is your opportunity to get published in *IG Living* magazine! Submit your entry by June 1.

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**Research**

**IDF Awarded Funds to Develop Health Data Network**

A team led by the Immune Deficiency Foundation (IDF) has been awarded funds by the Patient-Centered Outcomes Research Institute (PCORI) to develop and expand a health data network that will be part of PCORnet, the National Patient-Centered National Clinical Research Network. IDF’s PI Connect data network is one of 29 that were approved for a total of $93.5 million from PCORI on December 1 to form a national resource to boost the efficiency of health research.

PCORnet is a secure national data network that will integrate data from the 29 networks to provide access to a large amount of diverse and nationally representative health information that can support a range of study designs. It is intended to reduce the time and effort needed to launch new studies and to focus research on questions and outcomes useful to patients and those who care for them. PCORnet also will join together networks operated by both patient communities and health systems to interact and jointly determine research priorities such as the selection of specific studies to support.

Led by principal investigator Kathleen Sullivan, MD, PhD, of Children’s Hospital of Philadelphia, the IDF-led team will use the PCORI funds to expand and improve its systems, work to standardize its data and be part of the process to develop policies governing data sharing and security and protection of patient privacy. It also will refine its network’s capacity to engage and recruit patients and other stakeholders interested in participating in research.

“Currently, two unique data sets for primary immunodeficiency diseases (PI) exist: the IDF eHealthRecord, an electronic personal health record for patients with PI, and the United States Immunodeficiency Network patient-consented registry, a data-validated registry of clinical information,” explained Dr. Sullivan. “For those patients who choose to participate, PI Connect will provide the opportunity to meld these two data sets to maximize the breadth of data on PI and accelerate understanding and treatment of these rare diseases.”

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Legislation

HHS Strengthens Patients’ Right to Access Lab Reports

On Feb. 3, the Department of Health and Human Services (HHS) issued a final rule that amends the Clinical Laboratory Improvement Amendments of 1988 (CLIA) regulations to allow laboratories to give a patient, or a person designated by the patient (his or her personal representative), access to the patient’s completed test reports on the patient’s or patient’s personal representative’s request. At the same time, the final rule eliminates the exception under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule to an individual’s right to access his or her protected health information when it is held by a CLIA-certified or CLIA-exempt laboratory. While patients can continue to get access to their lab test reports from their doctors, these changes give patients a new option to obtain their test reports directly from the lab while maintaining strong protections for patients’ privacy. “The right to access personal health information is a cornerstone of the HIPAA Privacy Rule,” said HHS Secretary Kathleen Sebelius. “Information like lab results can empower patients to track their health progress, make decisions with their healthcare professionals, and adhere to important treatment plans.”

The final rule is issued jointly by three agencies within HHS: the Centers for Medicare and Medicaid Services (CMS), which is generally responsible for laboratory regulation under CLIA, the Centers for Disease Control and Prevention, which provides scientific and technical advice to CMS related to CLIA, and the Office for Civil Rights, which is responsible for enforcing the HIPAA Privacy Rule.
Researchers at the Yale School of Medicine have identified a genetic mutation that causes lupus, an autoimmune disease without a known cure. In the study, the researchers did not intend to investigate the genetics of lupus, but instead tried to identify how a DNA repair mechanism distinguishes between correct and incorrect DNA bases. To answer this question, they mutated the DNA repair gene POLB in mice thinking the mice would exhibit symptoms of cancer. Instead of cancer, the researchers began to see symptoms of lupus. Most conspicuously, they noticed that the mice had elevated levels of antinuclear antibodies, a classic marker of lupus. “For a long time, people thought that mutations in DNA repair genes could be linked to lupus, and this is actually one of the first demonstrations that a mutation in a DNA repair gene is actually linked to lupus,” said Joann Sweasy, study author and professor of therapeutic radiology and genetics at the Yale School of Medicine. Sweasy believes the reason for this elevation might be that the mutated POLB gene was creating antibodies that attacked the animals’ own cells, leading to lupus.

The findings hold promise for helping physicians diagnose lupus and researchers develop treatments. The study was published in Cell Reports on Jan. 16.

A new treatment that boosts immunity to the Epstein-Barr virus (EBV) may benefit patients with multiple sclerosis (MS). The Australian study published in the Multiple Sclerosis Journal tested a new treatment that boosts the ability of CD8 T cells in the immune system to fight EBV. The treatment involves taking some of the patient’s blood from which T cells are harvested and grown in the lab together with an EBV vaccine. The boosted cells are then transferred back to the patient intravenously. The researchers believe the approach, called adoptive immunotherapy, could potentially treat MS and other chronic autoimmune diseases.

One patient in the study was a 43-year-old man who has been unable to walk or transfer himself without assistance since 2008. He had his first MS attack in 1994 and was diagnosed with relapsing-remitting MS in 2000, which later developed into secondary progressive MS. After being given a six-week course of the treatment, he started to show signs of clinical improvement within two weeks of starting treatment, including improvements in attention, memory, thinking and hand function, a reduction in fatigue and painful spasms, and increased work productivity. An MRI scan of his brain showed decreased disease activity, his cerebrospinal fluid showed a decrease in antibodies, and at the latest follow up at 21 weeks, there was some improvement in leg movement. The therapy appeared to produce no adverse side effects.

“The beneficial effect of boosting immunity to EBV by this treatment highlights the importance of impaired immunity to EBV in the development of MS,” said Michael Pender, a professor at the University of Queensland School of Medicine, Brisbane. “We believe the treatment corrects the impaired CD8 T cell immunity that allowed EBV infection to cause MS.”

The researchers say the treatment now needs to undergo a clinical trial to test its safety and effectiveness in a larger sample of patients with varying forms of MS. In February 2013, Medical News Today reported how another team of researchers in the U.S. discovered new clues to EBV that they hope will help researchers explore unexplained links between EBV, autoimmune diseases, malaria and cancer.
Imagine caring for your child with hemophilia with no factor, refrigerator, running water, electricity, or transportation to a clinic.

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Caring for people with hemophilia around the world—one at a time.

Meeting
8th Annual Neuropathy Action Awareness Day Is June 11th

The Neuropathy Action Foundation (NAF) is hosting its 8th annual Neuropathy Action Awareness Day on Wednesday, June 11, at the Intercontinental Los Angeles/Century City Hotel in Los Angeles, Calif. The event provides an opportunity for patients to interact with other patients, providers and exhibitors. Sessions will focus on traditional and alternative diagnoses, treatment options, sleep disorders, diabetes and medical laws. The event also includes a sit-down luncheon, exhibit area, a celebrity speaker, elected officials and a silent auction. The cost is $20 for patients and caregivers. A registration form can be found on the NAF website at www.neuropathyaction.org.

Individuals who are unable to attend in person, can view the event via live streaming on the Internet free of charge. Those individuals also will be able to ask questions of speakers and receive answers in real time. And, since the event will be recorded, it can be watched on another date on the NAF website. The link to view the event online is located on the registration form. More information can be obtained by calling (877) 512-7262.

Resource
IG Living Publishes First eBook!

For over three years, the IG Living blog has given voice to the life experiences of patients and caregivers in the IG community. Now, the best of these reflections is being captured in a new book titled Life With IG: Inspirational and Heartfelt Perspectives from the Front Lines of Chronic Illness. The highly anticipated eBook will be available for purchase and download later this spring.
A NEW WAY OF PRACTICING MEDICINE

The story of how one patient was diagnosed with a life-threatening condition illustrates how the changing healthcare landscape might affect the quality of physician care.

By Sue Romanick, MD

As I entered the exam room to meet Bob for the first time, I smiled with relief. Bob looked pleased to be in our clinic, appearing well-tanned and comfortable. I had already noted the priority that he had scrawled on the intake form for today’s visit: “ear wax.” I was relieved that this would be a straightforward visit. Because several patients that day had complex issues, I had already fallen behind in my schedule, and my staff had nervously pointed out that the waiting room was full. Yet, I must admit I was curious why Bob had come to me.

Bob knows I am a rheumatologist who deals with autoimmune disorders. Yet, he had insisted on seeing me when he made the appointment. His wife was already a patient, although they had been living in Hawaii for a few months. This visit was rather spur of the moment, so I was happy to help out.
After reviewing Bob’s three detailed medical history forms, including his past medical history and medications, my examination confirmed that Bob, indeed, did have impacted ear wax in his right ear. There was no infection, and he appeared to be otherwise healthy. So, we discussed treatment options, and Bob opted for a simple, over-the-counter remedy.

Bob appeared pleased with my assessment. It felt like the visit was over, and I closed my laptop and moved toward the door. Little did I realize that a bombshell was about to drop. As my hand landed on the door handle, all of a sudden, Bob uttered words that have alarmed many a provider: “Doc?” he stated with hesitation and a meek, upward inflexion in his voice. “Can I ask you another question? I have this pain.… ”

“Oh, and by the way….” How many times has a medical provider heard that? In truth, this can indicate a dangerous path depending on which fork in the road the provider takes. In the current healthcare environment, the right answer was to tell Bob to book another appointment. After all, providers get rated by patients these days. I knew it was unfair to keep my other patients waiting, and I sure didn’t want a negative review. Even more importantly, I knew that health insurance companies rate their providers based on customer care, and they collect input from patients about how long their waits are. Yet, simply telling Bob to book another appointment was not the real me. It was not my style to send my patients out the door with a big question mark.

“Pain? Since when?” I asked, trying to hide the disappointment in my voice. My mind was reliving vignettes of life in slow motion. As Bob answered “three weeks,” several vignettes played out in my mind, one of which was the “audit.”

**Audits: The Time Thief**

I had to make a decision concerning Bob. My staff was getting impatient looks from the waiting room, and Bob had already used up his appointment time. Would I make Bob my priority or the other patients still waiting to be seen? I felt guilty for making the patients in the waiting room wait, and I felt equally guilty knowing that I would be keeping my own family waiting longer for me to get home that evening.

There is good reason for patients to question whether the days of the kind and patient doctor are on their way out. Being in private practice, I’m already overwhelmed by the impact of healthcare changes due to new regulations that are supposed to help patients get better medical care. The impact of these gradually adopted changes is being felt in full force by those of us in private practice in smaller clinics (and our numbers appear to be dropping like flies). In large institutions, the impact of these changes may be diluted through the higher numbers of administrative personnel. Yet, discussions with colleagues behind closed doors in both settings suggest a system both burdened and overwhelmed.

**There is good reason for patients to question whether the days of the kind and patient doctor are on their way out.**

Many healthcare providers are dreading, rather than welcoming, the coming changes. For many years, doctors have peered down microscopes to learn why patients are sick and how best to help them. These days, the microscopes are turned around, and doctors are finding themselves subjects of magnification and scrutiny. These microscopes peer down on healthcare providers from different angles to judge their competency in areas unrelated to, and taking the focus away from, providing quality and effective medical care.

It is unclear who is driving these changes in healthcare. But, insurance companies are playing a large role. These companies regularly perform audits on providers — audits that are conducted by nonmedical personnel who evaluate patients’ healthcare records by systematically going through a list of bullet points to ensure benchmarks are met: “chief complaints” — how the reason(s) behind the medical visit are worded; “history of the presenting illness” — the list of descriptors in the story behind the medical problem; “review of systems” — how the rest of the patient’s mind and body are doing; a review of medication and other allergies; up-to-date medication lists; past medical and family medical histories; social history; lifestyle issues; the physical examination; the complete medical assessment; and plans and recommendations that...
specifically document what was discussed, being sure that a recommendation for returning to the clinic was stated and documented. Whew! If the insurance administrator finds even small deficiencies in the audit, the provider may not be reimbursed what would have been customary payment for the visit, even if additional time was spent with the patient to ensure he or she understood the tests, diagnoses or treatment.

Yet, to date, there has been insufficient evidence that these benchmarks tracked by the audits truly affect quality of patient care. Unbelievably, this shows clear lack of confidence in what providers have been taught in medical school. For providers, it is an apparent exercise in futility that requires even more administrative time, usually after hours or on weekends. Instead of taking their children to the park, providers are in their office wading through health-insurance-generated red tape. In fact, since my office changed from paper to electronic medical records, I am spending an extra two hours every work day trying to meet audit standards for charting. The current goal of recreating an office visit from the list of provided codes requires the coding skills of a librarian and the detailing ability of an accountant. This has nothing to do with real doctoring. It is time that is not reimbursed. And, it is time taken away from patient care.

And, beware a new “time thief” on the horizon! In addition to providing information for the insurance audits, providers now have to participate in registries that require them to electronically send information about patients’ private health information and treatment to a third party. This is not simply a point-and-click situation. This information must be entered into separate electronic documents. Currently, there is both a carrot-and-stick approach with some of the audits and registries. Not participating can lead to significant financial loss for providers, which translates to even lower reimbursement when reimbursements are already falling.

Why are these audits truly needed? A recent discussion with an employee of one of these companies revealed their real purpose is building profiles of providers and classifying them based on company criteria to determine how much a patient must pay out of pocket for treatment. For example, a provider who sees more challenging patients might be considered a more expensive provider. If so classified, the insurance company could force the patient to pay more out of pocket for a visit with that provider. So, if a patient has joint pain, the insurance company will steer that patient toward the “cheaper” doctor to both save the company money and to successfully make the patient feel he or she has saved money as well!

Obviously, the insurance company can save money if the patient chooses a cheaper doctor. And, obviously, patients will be tempted to choose a cheaper doctor. But what if a patient has medical issues that are challenging and require more complex, more comprehensive or more compassionate workup? Is it fair that the insurance companies are dictating how patients can choose their providers?

Gone are the good old days when a doctor could look each patient in the eye with sincere compassion and convey concern and empathy. Now, our eyes are trained on the computer screen.

**Reimbursement: Cost vs. Care**

With Bob’s last-minute question still lingering, how my hand wanted to depress that door handle and keep moving! But my feet froze to the floor. Indeed, slowly and thoughtfully, I removed my hand from the door handle, and I turned to face him: “Pain where?” Bob answered timidly, motioning to where his liver should be: “Here. Right here.”

I asked Bob: “How long have you had this pain?” He was a little noncommittal: “I’ve had it about three weeks, Doc. It’s not too bad.” As I stood there, I tried to build a quick mental list of pains that stick around for three weeks. I’d have preferred he had said three months or three days or even three hours. I could have more easily come up with explanations in each of those cases. Then, it would be easy for me to conduct the physical examination to address the usual diagnoses and to order the appropriate tests. But, the quick survey that flashed through my brain came up empty-handed and, instead, raised a red flag that something sinister was going on. I didn’t know what, but I had to find out. I couldn’t just send him home because the red flag would not leave my intuition.

Leaving the exam door closed, I asked Bob to lie down on the exam table. What could be so elusive that, if serious, I could be missing on examination? I checked his breathing, blood pressure and pulse. They all checked out fine. His heart and lungs sounded normal. There was no swelling in a foot or leg. He was not uncomfortable when I pressed over his liver, nor over the rest of his abdomen. I was stymied.

Three weeks? Could this be a local infection? But, Bob had no fever, jaundice, rash, swelling or any other signs of serious nature. At this point, it would not be unusual for a provider to order a test such as an ultrasound of the liver.
and gallbladder, or a flat plate (X-ray) of the abdomen. But, my intuition told me that a history of pain for specifically three weeks was unusual, especially over the liver. These usual tests for abdominal pain could turn out to be dead-ends. Something just didn’t add up. So, I did the unusual, even though it could face scrutiny later.

Providers are finding it increasingly difficult to prescribe the best medication for patients without worrying about the patients’ insurance companies denying reimbursement. That’s why preauthorizations are necessary, but they are also potentially dangerous. I have been in my clinic on a Sunday to discover a non-urgent notice from an insurance company that a medication for which I had written an urgent prescription a few days before (a corticosteroid) had been denied to the patient. When I tried to contact the office number provided to get the necessary authorization, I was met with a recording saying that they were not open on Sundays. In my field, there are conditions like giant cell arteritis for which withholding this type of medication, prednisone, can lead to blindness. Furthermore, no other medication can be substituted, and it must be given in a timely fashion.

No one can dispute that the required preauthorizations, which involve filling out forms, copying portions of patient records, and spending excessive time on the phone waiting to speak to nonmedical and medical representatives of the insurance companies in order to get an OK for a diagnostic test or specific type of medication, pose a time and administrative burden on medical clinics. A simple understanding of basic human nature would reasonably predict that this burden would result in fewer tests and medications being ordered (and, therefore, decreased healthcare costs) simply because of the “nuisance factor” to providers. Preauthorizations should more aptly be named “deterrents.” Unfortunately, these deterrents adversely affect the quality of healthcare.

Fortunately, in Bob’s case, the direction I opted to take didn’t require preauthorization. I have always learned a lot about patients at the bedside, even when others have opted for expensive tests. Asking Bob to lie back comfortably, I took the stethoscope and placed it gently just below Bob’s ribs on the right side of his abdomen. I’m sure that some of my past mentors would have laughed when I did this. The liver itself, even when “sick,” does not produce any unusual sounds. But, what I heard was astounding and unusual. It was as if one were listening to someone with a mouth full of food breathing slowly but noisily, in and out, through clenched teeth. But, in this case, Bob’s mouth was nowhere near this area!

As soon as I heard this ugly noise, a light bulb went off. Bob had traveled from Hawaii three weeks before, which meant that he had been sitting in a plane for several hours — a set-up for a possible blood clot. But, while Bob had no health factors whatsoever for a blood clot, I could not deny that a blood clot that had originated from a leg during the trip and had traveled to his right lung could produce such a sound, audible only through a stethoscope. The good old-fashioned physical examination that cost nothing beyond the standard visit had to be believed. I called the emergency department and reported that I had an emergency for them. They were interested but not totally convinced as Bob had no other signs: no shortness of breath, no true chest pain, no cough, nor any swelling in either of his legs. On top of that, he was trim and fit. Was I sure? Or, could I be wrong?

Providers are finding it increasingly difficult to prescribe the best medication for patients without worrying about the patients’ insurance companies denying reimbursement.

I explained to Bob that it was better to get checked out even if the odds were low. Two hours later, the emergency room physician called me personally. Bob’s workup showed a surprisingly large blood clot in the right lung that would have killed him within 48 hours. It had been growing over three weeks. He was so fit that his body had been able to fully compensate for the increasing loss of lung function. He was admitted to the intensive care unit and started on blood thinners. A life had been saved.
“New and Improved” Quality of Healthcare

Of course, there is more to Bob’s story. It seemed that Bob was not through stumping his doctors. He had returned to Hawaii after he was stabilized on his blood thinner medication for the blood clot in his lung. And, he had completed his blood-thinning treatments and had managed to stay out of medical clinics since his clot had resolved. But, almost exactly one year since he had first arrived in my office from Hawaii, he was back for a visit, this time presenting with the telltale look of worry in his eyes and explaining: “Doc, I have a pain in my stomach.” Alas, this was not simply a matter of: “Here we go again!”

This time, when Bob announced abdominal pain, I feared the worst. In fact, I was not deterred by his bedside examination being completely normal. I tried to be extremely thorough. As before, I had to keep the next patient waiting longer while I spoke with a radiologist to schedule an urgent abdominal CT scan that afternoon.

Previously, I had wondered how his clot could have developed so easily without obvious risk factors. I was concerned that his blood could have developed a clotting problem due to some sort of tumor. Surprisingly, none of his doctors in the hospital or his family doctor had ever discussed this possibility with him. Even though it felt premature, I took extra time with Bob to explain why I needed him to see a cancer doctor. He was, of course, shocked that I brought this up so soon in our discussion. But, I knew intuitively that he could better cope with a bad diagnosis if we had the wheels of achieving wellness in motion. Later that evening, after hours, the radiologist phoned me. Bob had a tumor in his pancreas. This is one type of cancer that can cause the blood to clot unexpectedly. At least Bob was now linked to a cancer doctor in whom Bob knew I had full confidence. That softened the blow of a dreaded diagnosis and allowed Bob to start gaining some sense of control of a serious situation.

Bob’s case is not isolated. Serious, unexpected medical diagnoses have been made in our clinic when only simple, routine appointments have been booked. It is increasingly difficult to keep all patients happy all the time, especially those who have difficulty waiting, and we make every effort to ensure patients’ expectations for waiting are respected. Yet, had I been on time for some of these patients, I would have missed the unexpected findings in the patient before them that indicated a potentially life-threatening condition. I doubt Bob would disagree with this.

Surely, saving lives and limiting disability reflect the true quality of healthcare? Yet, the simple satisfaction of trying to be compassionate with one patient can be diminished by huge administrative demands imposed by insurance companies. And, there appears to be no way to communicate this to these companies. So, what’s my take on where healthcare is going? It is increasingly difficult to be a compassionate and comprehensive physician when I have to keep an eye on the clock and both eyes focused on the computer screen, while keeping at least one eye on the financial bottom line — in a climate in which office expenses and demands on my free time are growing, especially while reimbursements and family time are decreasing. In this healthcare environment, the public should be increasingly concerned about physician burnout.

SUE ROMANICK, MD, is board-certified, as well as recertified in both general internal medicine and rheumatology. She was involved with immunology research on cell clones at the German Cancer Research Institute in Heidelberg, Germany, and has worked in immunology and plasmapheresis at the University of California, San Francisco. Dr. Romanick is a public speaker and has spoken for the Arthritis Foundation, University of Washington and Overlake Hospital in Bellevue, Wash. She also has participated in lobbying efforts on Capitol Hill to support arthritis patients, both young and old, at the request of the American College of Rheumatology. She runs her own private practice clinic in Bellevue, Wash.

Editor’s note: The name of this patient has been changed to protect his privacy.
For people with primary immunodeficiency

Hizentra now offers even more freedom and flexibility

Now approved for biweekly (every 2 weeks) dosing

- The first and only 20% SCIg—now with the flexibility of biweekly administration

Now available in a convenient 10 g (50 mL) vial

- May reduce the number of vials patients need to handle and administer

Important Safety Information
Hizentra is indicated as replacement therapy for patients with primary humoral immunodeficiency (PI), age 2 and older. This includes but is not limited to the humoral immune defect in congenital agammaglobulinemia, common variable immunodeficiency, X-linked agammaglobulinemia, Wiskott-Aldrich syndrome, and severe combined immunodeficiencies.

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

Please see additional Important Safety Information on reverse side and brief summary of full prescribing information for Hizentra, including boxed warning, on adjacent page.
Hizentra —
the first and only 20% SClg therapy

- Delivers steady-state Ig levels in half the volume of 10% Ig products*
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- Does not require refrigeration, so patients can infuse anytime, anywhere

Now available in a convenient
10 g (50 mL) vial

Important Safety Information (continued)

Hizentra is contraindicated in patients with a history of anaphylactoid or severe systemic reaction to human immune globulin preparations or components of Hizentra, such as polysorbate 80. Because it contains the stabilizer L-proline, Hizentra is contraindicated in patients with hyperprolinemia. Hizentra is also contraindicated in patients with immunoglobulin A deficiency who have antibodies against IgA and a history of hypersensitivity.

Hizentra should be administered subcutaneously only. Do not administer intravenously.

IgA-deficient patients with anti-IgA antibodies may be at greater risk of developing potentially severe hypersensitivity and anaphylactic reactions with administration of Hizentra. If hypersensitivity occurs or anaphylactic reactions are suspected, discontinue administration immediately and treat as medically appropriate.

Monitor patients for aseptic meningitis syndrome (AMS), which has been reported with SCIg. In patients at risk of acute renal failure, monitor renal function, including blood urea nitrogen, serum creatinine and urine output. Also monitor patients for clinical signs of hemolysis or transfusion-related acute lung injury (TRALI).

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

The most common adverse reactions (observed in 5% or more of study subjects receiving Hizentra) were local reactions (i.e., swelling, redness, heat, pain, and itching at the injection site), headache, diarrhea, fatigue, back pain, nausea, extremity pain, cough, rash, pruritus, vomiting, upper abdominal pain, migraine and pain.

Ig administration can transiently impair the efficacy of live attenuated virus vaccines, such as measles, mumps and rubella. It can also lead to misinterpretation of serologic testing.

Please see additional Important Safety Information on reverse side and brief summary of full prescribing information for Hizentra, including boxed warning, on adjacent page.

*Based on an equivalent dose in grams.


Hizentra is manufactured by CSL Behring AG and distributed by CSL Behring LLC.

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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 an Immune Globulin Subcutaneous (Human) (IGSC), 20% Liquid indicated for the treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

DOSAGE AND ADMINISTRATION

For subcutaneous infusion only. Do not inject into a blood vessel. Administer weekly or biweekly (every two weeks).

Dosage
Before switching to Hizentra, obtain the patient’s serum IgG trough level to guide subsequent dose adjustments.

Weekly: Start Hizentra 1 week after last IGIV infusion

Initial weekly dose = \( \frac{\text{Previous IGIV dose (in grams)}}{\text{No. of weeks between IGIV doses}} \times 1.53 \)

- Biweekly: Start Hizentra 1 or 2 weeks after the last IGIV infusion or 1 week after the last weekly Hizentra infusion. Administer twice the calculated weekly dose.
- Adjust the dose based on clinical response and serum IgG trough levels (see Dose Adjustment).

Administration
- Infusion sites – 1 to 4 injection sites simultaneously, with at least 2 inches between sites.
- Infusion volume – First infusion, up to 15 mL per site. Fifth infusion, up to 20 mL per site; then to 25 mL per site as tolerated.
- Infusion rate – Up to 15 mL per hr per site. Increase to 25 mL per hr per site as tolerated.

ADVERSE REACTIONS
The most common adverse reactions observed in ≤5% of study subjects were local reactions (i.e., swelling, redness, heat, pain, and itching at the injection site), headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, rash, pruritus, vomiting, abdominal pain (upper), migraine, and pain.

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.

USE IN SPECIFIC POPULATIONS

- Pregnancy: No human or animal data. Use only if clearly needed.
- Pediatric: No specific dose requirements are necessary to achieve the desired serum IgG levels.

Based on September 2013 version
He may have been exaggerating, but a family friend, an experienced and respected doctor, recently told me something shocking: If we were living before the year 1900 and became sick, there was a better chance at a positive medical outcome by staying home rather than going to see the doctor. While I have yet to verify his claim, the gist of it — that healthcare has improved that much over such a relatively short period of time — gave me some perspective on today’s ongoing debates about healthcare reform. It was a reminder that, while we live in a time when the healthcare system is routinely criticized, it has been so much worse.

By Carsten Schmiedl

Tips for Navigating Healthcare’s New Terrain

With some preparation and a little knowledge of what happens behind the scenes, it’s still possible to get quality healthcare during doctor visits.
Still, there’s surely something to the ongoing debate on healthcare currently dominating mainstream news outlets across the country. The use of buzzwords such as “Obama care,” “Affordable Care Act” and, more generally, “healthcare reform” has become routine. We’re often inundated with arguments for and against it. Cautious optimists think that its benefits will outweigh its growing pains. The other side contends that the system is destined to implode, and must be rebuilt in a few years anyway. It seems the only reasonable conclusion we can glean from this debate is that the current system cannot remain the same. But, perhaps the most frustrating part is trying to grasp the practical implications — namely, how doctor visits themselves will be affected.

With healthcare’s ever-changing terrain, patients need some practical advice on how to navigate the system, including some background information to understand what goes on behind the scenes in healthcare, as well as some simple steps to make doctor visits more worthwhile.

Behind the Scenes of Healthcare

What many people don’t realize is that changes in healthcare are already under way — whether subtle, obvious or hidden entirely. An obvious sign of the changes in healthcare, visible across the country, is the increasing presence of electronic medical records (EMRs). EMRs simplify healthcare on many levels for doctors. From a practical perspective, for example, they aim to eliminate much of the busywork innate in having paper-only charts. They also reduce the chance of losing papers from charts or rendering any of its pages unreadable.

Further, EMRs are indispensable to the success of healthcare reform. Information registries, for example, will hopefully make it easier for researchers to gather information en masse about the quality of healthcare. Some EMR systems have built-in features allowing providers to easily export information about patients to outside registries, where the information is analyzed and passed on to decision-makers. The hope is that the data entered in these registries will help identify effective treatment plans. The downside is that some “researchers” who may gain access to registry data are employed by insurance companies that use this data to determine whether doctors meet their companies’ standards of care, oftentimes limiting the amount of tests doctors can perform to assist them in providing quality medical care.

In addition to the research opportunities these information registries provide, patients should be aware of how their information is shared. We’re all familiar with Health Insurance Portability and Accountability Act (HIPAA) regulations and the idea of doctor-patient confidentiality — namely, that the personal health information shared with doctors is protected. Providers, however, are increasingly under pressure to submit information about their patients to these registries. And, as part of their contract with insurance companies, providers must produce patient charts whenever insurance companies request them. I can attest that these insurance audits happen frequently. While these third parties have policies in place to protect patient privacy, there is a risk because patient information is more vulnerable every time it leaves the clinic.

Unfortunately, there is a more obvious consequence of EMRs: less patient-doctor eye contact. While this may seem insignificant, patient-doctor communication is where healthcare is truly delivered. With paper charts, there were fewer obstacles. Clinic notes were less structured, and there was less information to input. But with EMRs, even for routine visits today, doctors must now ensure that everything is filled out. These are requirements that can hinder the art of medicine. Ironically, I’ve heard chief surgeons complain that their residents’ chart notes are becoming less individualized and more standardized; because of stricter documentation requirements, the residents template almost all information, and include less information about the patient. Whether patient outcomes are ultimately improved remains to be seen. But for now, they clearly come at the cost of lengthier patient-doctor interactions.

The documentation requirements of EMRs have also resulted in an expansion of the healthcare team. Clinics now must include a technical support team to ensure that they run smoothly. Of course, this comes at additional cost. The common thread seems to be that efforts to improve quality of care appear to demand less medical work and
more administrative work from healthcare providers. In October 2013, Harvard Medical School economist Dr. Michael Chernew began a study to measure the effectiveness of these quality control measures.

Steps to Make Doctor Visits Successful

The good news is that great healthcare is still possible in today’s healthcare climate. And, having an understanding of what goes on behind the scenes, before and after the visit, goes a long way toward making clinic visits more satisfying. The patient-doctor relationship is, after all, a two-way street. For a visit to be successful, it requires that both sides play their roles effectively. Just as your doctor wants to know your story, knowing about the current state of healthcare creates more trust and more effective communication.

The good news is that great healthcare is still possible in today’s healthcare climate.

Time is at a premium in today’s medical clinics, perhaps more than ever — especially considering the impending influx of citizens into the healthcare system and the shortage of doctors that is sure to result. So, something as simple as coming to clinic visits prepared and with reasonable expectations goes a long way. A great first step is for patients to know specifically what they would like to accomplish during their visit and be able to explain it in a concise manner. On one of the forms in our clinic, we have a small line on which patients write their “chief complaint.” This is the main problem that the doctor will address during the visit. There’s nothing doctors dread hearing more at the end of a visit, when their hand is on the doorknob, than “Doctor, I have another question.”

There are several other ways patients can make their visit more successful. Writing down questions beforehand can help patients organize their thoughts and will help them leave their visit satisfied. Stating their priority at the beginning of the visit ensures that there’s adequate time to address their concerns. No one likes waiting, but the new documentation guidelines are causing delays in the room and for the medical clinic. So patients should bring their smartphone, laptop or book with them to make their wait more enjoyable and productive. If they prefer to reschedule because they cannot wait, they should never be afraid to do so. The more at ease they are during their visit, the better.

Finally, selecting the right provider can be almost as important as the visit itself. But how do patients know who is right for them? There’s no single method because medicine is not your average consumer-based industry. Put simply, patients’ health is at risk. The best resources are the ones with expertise. Personal references, such as people the patients know who recommend a provider, may be a good place to start. Patients’ primary care providers are also a great resource, not only because they know the patients, but because they have medical expertise. There are also certain medical societies, or sub-specialty colleges such as the Immune Deficiency Foundation and the American Academy of Allergy, Asthma & Immunology that can recommend specialists in patients’ areas.

And, patients need to be aware of the limitations of online reviews. While they tell the opinions of a small group of people, most reviewers do not have medical expertise and often have a hidden agenda. Review websites have their own agendas as well. They often recycle reviews off of other websites to generate traffic. At the same time, they attempt to entice providers to sign up for services to remove bad reviews. These services are not free, and one major review site that advertised to our clinic charges hundreds of dollars per month to “clean up reputations” diminished by bad reviews. This certainly suggests a conflict of interest.

Still Bedside Medicine

Despite ongoing healthcare changes, medicine is still practiced at the bedside, between patients and their providers. Doctors are highly trained professionals. They are entrusted with taking care of the sick and are often required to make judgment calls when the choices are not obvious. There’s a certain artistic quality to medicine that I believe motivates many providers every day. By choosing the right provider and spending their time wisely, patients will be on their way to receiving excellent healthcare, even as healthcare changes swirl around them.

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Patient Advocacy: How Patients Can Gain Control

Patients will feel more in control over their healthcare situation if they are informed, understand their rights and advocate for themselves.

By Annaben Kazemi
Millions of patients and caregivers across the U.S. are faced with illnesses and difficulties accessing healthcare. These individuals find themselves trapped in a maze of access issues, financial worries and emotional strain. No matter what the diagnosis, the process of getting the best healthcare is often rife with red tape and confusion.

For individuals with primary immunodeficiency diseases (PIDDs), one of the greatest challenges is finding the right information and resources when they need them. But, the more information they can obtain, the more capable they will be to make decisions that can ultimately impact their healthcare, long-term insurability and financial stability. Here are some tips to help these individuals advocate for a better personal healthcare experience.

Be Informed

Knowledge is power. Patients need to get educated about their particular health concerns before entering their doctor’s office. They should think preemptively about the treatment desired and whether it will work, rather than just appearing at their doctor’s office and asking for advice about a particular health condition. They can also conduct their own research and become educated about the various screenings, tests and treatments available. Antoinette Dziedzic, the nursing campus chair at the University of Phoenix Detroit Campus and former president of the Michigan Public Health Association, suggests preparing for medical appointments “by checking reliable online health resources to review the latest research or brush up on fundamentals.” She also recommends patients ask practitioners questions. The more patients learn about their diagnoses, the more in control they will ultimately feel.

All patients have the right to seek and receive all the information necessary to understand their medical situation. Patients on Medicare or Medicaid can review the benefits to find out if tests, items or services are covered. Understanding Medicare coverage, including Parts A, B, C and D, MediGap and Medicare Supplemental Plans, is a challenge for most patients. However, there are resources to help. One is A Clear View to Medicare published by the Patient Advocate Foundation. This clear and easy-to-understand booklet helps Medicare-enrolled patients and those eligible for Medicare make the most of their benefits. Another resource is the Medicare Coordination of Benefits Contractor, which can answer questions about who pays first.

More and more, patients find themselves struggling to meet out-of-pocket expenses associated with their medical and pharmaceutical needs and are seeking assistance. “Most hospitals have generous financial-assistance programs to help trim large bills even if your household income is above the poverty line,” states Tony Dale, founder and chairman of The Karis Group, an Austin-based patient advocacy and bill-mediation service. If patients are unable to pay the full amount of a bill, doctors’ offices often will offer an income-based sliding scale program. And, many pharmaceutical manufacturers have procedures. And, because health plans often change, patients should stay updated on the latest information.

For patients with multiple health insurance coverage, each type of coverage is called a “payer.” When there is more than one payer, coordination of benefits rules decide which one pays first. The primary payer pays what it owes on your bills first, and then sends the remaining balance to the secondary payer. In some cases, there may also be a third payer. This can be confusing, so questions should be asked and advice should be sought if it’s unclear which payer covers what.
patient assistance programs that serve as resource centers for patients. These pharmaceutical companies can help direct patients to internal and independent resources that help reduce the cost of medication for insured and uninsured patients, assist with insurance and pharmacy documentation, or generate the paperwork needed for appeals.

**Patient Rights**

Patients have certain rights. Some are guaranteed by federal law such as the right to get a copy of their medical records and the right to keep them private. Many states have additional laws protecting patients. And, healthcare facilities often have a patient bill of rights.

An important patient right is informed consent. This means that when patients need treatment, the healthcare provider must give all information needed to make a decision. Patients have the right to engage in conversation with the healthcare provider regarding options for therapies and services, regardless of health insurance policies. And, they have the right to refuse treatment or stop a procedure.

**Advocacy Resources**

Sometimes, patients need an advocate to help with the challenges of living with a diagnosis or illness. An advocate can be anyone who is willing to be an active liaison between patients and their insurers, employers and creditors. While a friend, family member, healthcare professional, social worker or educator can act as an advocate, there also are many organizations that offer free advocacy services to chronically ill patients.

Below is a list of organizations providing information and online resources and referrals. Many offer free advocacy services.

Patient Advocate Foundation (PAF) is a national 501(c)(3) non-profit organization that provides professional case management services to Americans with chronic, life-threatening and debilitating illnesses. PAF case managers serve as active liaisons between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters as they relate to their diagnosis. These liaisons are assisted by doctors and healthcare attorneys. [www.patientadvocate.org/resources.php](http://www.patientadvocate.org/resources.php)

The Immune Deficiency Foundation (IDF) Advocacy Center was created to help solve some of the problems that the primary immunodeficiency disease community faces. IDF’s full-scale program at both national and state healthcare levels focuses on one main concern: access to quality care. This includes access to all treatments, all sites of care and specialists. [primaryimmune.org/idf-advocacy-center](http://primaryimmune.org/idf-advocacy-center)

Patient Services Inc. evaluates individuals’ financial, medical and insurance situations to determine if they are eligible for premium or co-payment assistance. The organization provides help for many illnesses and offers many types of financial assistance. [www.patientservicesinc.org](http://www.patientservicesinc.org)

At healthcare.gov, individuals can learn about, compare and apply for insurance plans. A simple tool allows them to preview marketplace health plans and view price estimates without filling out an application. Also included are important details such as deductibles, co-payments and out-of-pocket maximums, as well as links to a summary of benefits, the provider network, drug coverage rules and customer service contacts. [www.healthcare.gov](http://www.healthcare.gov)

InsureUSToday provides information on the Affordable Care Act and insurance marketplaces to inform individuals how the law benefits them. Included is a contact form where individuals can ask specific questions of a professional case manager. [www.insureustoday.org](http://www.insureustoday.org)

Co-Pay Relief is a patient assistance program to help those who meet certain qualifications pay for out-of-pocket expenses for prescriptions and/or treatments. [www.copays.org](http://www.copays.org)

Medicare.gov provides information on Medicare, resolving disputes and help with costs and benefits. [www.medicare.gov](http://www.medicare.gov)

At the National Health Council Resource Directory, patients with chronic diseases and disabilities and their family caregivers can find links to various patient advocacy groups, government services and useful resources. [www.nationalhealthcouncil.org](http://www.nationalhealthcouncil.org)

IG Living’s Ask the Experts is a question-and-answer resource for patients with issues related to immune-mediated diseases. Patients’ information is kept confidential. [www.igliving.com/asktheexperts.aspx](http://www.igliving.com/asktheexperts.aspx)
Patients also have the right to choose medical personnel who can deliver quality healthcare for their disease state. If they so choose, patients have the right to request second opinions or consultations without consequence. Should there be concerns, problems or complaints about the quality of care or service received, a formal grievance may be filed.

Any decision rendered by the health plan can be appealed (most plans provide information in the EOC booklet on the appeal process). Kevin Lembo, the first healthcare advocate for the state of Connecticut, tells patients and their caregivers: “Any time you’re on the phone with your insurer, take notes: the date, what you asked, what they answered. If you need to appeal a claim denial, it helps to have a paper trail.”

Health plans are required to follow state and federal rules for handling their enrollees’ complaints and appeals inside the health plan, known as an “internal review.” And, many states have additional legislative procedures outside of the health plan, called “external reviews” or “independent reviews,” to provide an unbiased way to resolve disputes between patients and their health plans. An external review is a reconsideration of a health plan’s denial of service, with the review conducted by a person or panel of individuals who are not part of the plan.

**Be an Advocate**

Frequently, patients find themselves acting as their own advocates. Being proactive puts patients in control of healthcare outcomes. Here are some key points for those advocating for themselves:

- **Study before the appointment.** Trisha Torrey, a patient advocacy expert, says that showing up with a stack of computer printouts can imply that patients think their research equals another person’s years of experience. Instead, patients should study information online, and then say, “I’ve seen articles about a new type of treatment; what do you know about it?”

- **Ask any and all questions.** Patients should ask pharmacists, nurses and physicians questions concerning treatments or any prescribed medication’s purpose, proper dose, side effects and drug interactions. Also, they shouldn’t hesitate to inquire if any alternative treatment options exist.

- **Track down a receptive healthcare provider.** Patients should find a provider with whom they are comfortable confiding their health prognoses and concerns, even if this means seeking second and third opinions. Dr. Paul Haidet, staff physician at the DeBakey VA Medical Center in Houston, emphasizes that “the ideal doctor-patient relationship is like a meeting of two ‘experts.’ The doctor comes to the meeting with medical expertise. The patient is entering with contextual knowledge.”

- **Know insurance benefits and coverage, and review bills monthly.** Caryn Isaacs, a nationally recognized health policy analyst, regulatory expert and professional patient advocate, recommends patients ask for itemization of bills and clarification. In addition, patients should check to see if that doctor’s office offers different fees. A lot of times, they can get a negotiated rate if they can’t pay the full amount of a medical bill.

**An important patient right is informed consent.**

- **Keep proper documentation.** A detailed log of all appointments, conversations and medications should be kept. When on the phone or at appointments, patients should take notes. And, they should keep an organized file (either electronically or physically) of medical conditions, treatments and financial statements.

- **Keep a health journal.** A journal can help patients organize and keep track of symptoms, changes in health and general wellness habits, as well as help keep them abreast of any changes, responses to treatment or other medical details that, in turn, they can share with their healthcare providers. Patients can jot down questions in the journal as they come to mind.

- **Find a support group.** Dealing with the complex aspects of an ongoing illness can cause anxiety and stress, so it is important for patients to have psychological and emotional support. H. Kenneth Schueler, the director of HKS Patient Advocates in New York City, advises that “disease advocacy groups can offer educational seminars, summaries of clinical trial results, emotional support and more.” To find one, patients can Google “advocacy” and the name of their disease.

**ANNABEN KAZEMI** is the patient advocate for IG Living magazine.
M any patients who are prescribed immune globulin (IG) therapy have concerns about whether the drug is safe during pregnancy. While there is no definitive answer to this, pregnancy is listed as a precaution for IG. For instance, WebMD states that “during pregnancy, this medication should be used only when clearly needed.” Of course, IG is clearly needed by immune-deficient patients, as well as many autoimmune disease patients. The good news, then, is that most physicians believe IG is safe during pregnancy, and that its benefits outweigh its risks. In addition, there are many case reports of patients being treated with IG with no adverse effects to the fetus.

**Benefits vs. Risks**

Upon a medicine’s approval, the U.S. Food and Drug Administration assigns it one of five pregnancy categories that indicate the potential of a drug to cause harm to the fetus if used during pregnancy (Table 1). Each category outlines whether clinical studies have shown any potential risks of the drug during pregnancy. IG falls under category C, which means that either no animal or human studies have been conducted or animal reproduction studies have shown drugs in this category to have an adverse effect on the fetus, but there are no well-controlled studies conducted on humans to date. IG’s potential benefits may warrant its use despite potential risks.

The current belief in the medical community is that IG therapy is safe during pregnancy. But, the decision to continue to infuse IG during pregnancy is one that should be made with the treating physician, and it should be based on a risk-benefit analysis. A standard risk-benefit analysis considers all the benefits of using a medication and weighs those benefits against the risks of potential adverse events that may be caused by the medication. For women who are pregnant, the risk-benefit analysis should consider both the benefits of the medication and the risk of adverse events to both the mother and the developing fetus. For IG, the risk-benefit analysis should also include the risk of stopping the medication. For example, someone being treated with IG for an immune deficiency may be at increased risk of developing serious infections if IG is stopped during pregnancy. Ideally, a patient with a chronic condition being treated with IG or any other drug should discuss pregnancy with her physician well in advance of becoming pregnant. This will allow for the development of a solid treatment plan to support both the mother and the baby during pregnancy.

**IG Dosing**

Currently, there is no specific protocol published for IG therapy during pregnancy. According to Dr. Marc Riedl, associate professor of medicine in the division of rheumatology, allergy and immunology at the University of California, San Diego, “it’s well-recognized that IgG trough levels will fall in the second and third trimesters due to placental transfer, blood volume and weight gain.” So, he says it is advisable to begin checking the trough levels of those with an immune deficiency during the second trimester and to make dose adjustments to keep IgG levels well within the normal range. And, toward the end of gestation, it may be necessary to increase the frequency of the infusions. “In my experience, antibody deficient patients do very well during pregnancy with these relatively simple measures,” says Dr. Riedl.

For patients with autoimmune conditions, IgG trough levels aren’t a valid test for determining the correct dosing adjustments. Instead, the best indicator is to assess the specific symptoms related to the condition prior to pregnancy with the goal of maintaining the patients’ symptoms at the same or improved levels. If during the course of pregnancy the patient declines clinically, the physician may consider a modest dose increase to regain control. According to Dr. Todd Levine, director of the department of neurophysiology at Good Samaritan Hospital in Phoenix, Ariz., he adjusts the IG dose for autoimmune disease patients only if symptoms get worse. Otherwise, he keeps his patients on the pre-pregnancy dose throughout gestation.

**Case Studies**

Several studies conducted in the past have assessed the safety of receiving IG during pregnancy. Most of these
articles are small case studies of patients who were receiving IG for a chronic condition prior to becoming pregnant, and continued to receive IG during the course of their pregnancy. And, each of the studies found it was safe to continue IG therapy with no adverse events noted for the mother or the baby. Three of these studies focused on patients with common variable immune deficiency who were treated with IG during pregnancy and whether dose adjustments were needed. The common result from each of these studies found dosing adjustment was necessary during the course of the pregnancy to keep IgG trough levels at pre-pregnancy levels. The need for increased dosing in the late second and third trimesters is thought to be due to plasma volume expansion. The studies also found that babies born to immune deficient patients who continued IG therapy during pregnancy had adequate IgG levels after birth, whereas babies whose immune-deficient mothers were not treated throughout pregnancy had slightly lower birth weights and presented with lower IgG trough levels. The studies did note, however, that low birth weight babies did develop normally and did not have any long-term impact.

Communication Is Key

While there are no current studies directed at testing the safety of IG treatment during pregnancy, current practical experience has found IG to be safe and effective, and the benefits of IG therapy are believed to outweigh the risks. However, each patient is different. Therefore, close communication between the patient, the IG prescriber and the Ob/Gyn physician throughout the pregnancy will allow for timely dose adjustments when necessary.

LESLIE J. VAUGHAN, RPh, is senior vice president of clinical services at NuFACTOR Specialty Pharmacy.

Reference

Sources
Let’s Talk!

By Trudie Mitschang

Once a serious runner, Tami Slaats has adapted her lifestyle to accommodate her diagnosis of CVID, and with subcutaneous immune globulin therapy, her health is getting better each year.

Tami Slaats was diagnosed with common variable immune deficiency (CVID) in June 2010, after 20 years of misdiagnosis and increasingly poor health. A former marathon runner and athlete, Tami has learned to accept her “new normal” while continuing to pursue her passion for health and fitness. After living in the Netherlands for two years, Tami currently lives with her husband, 6-year-old son and dog in Ann Arbor, Mich.

Trudie: What were your symptoms prior to diagnosis?
Tami: I spent approximately 20 years fighting numerous sinus infections every year. I remember one infection was so painful that it hurt my teeth to walk. During this time, I became more and more exhausted despite a good diet and exercising five times a week. I also started to become achy all over my body and thought it was just my stressful job and lack of quality sleep. Even after 10 hours, I would wake exhausted. The year before diagnosis, I was getting eight sinus infections a year and pneumonia. And, I struggled with heavy depression.

Trudie: Were you ever misdiagnosed?
Tami: I spent a good part of those 20 years being misdiagnosed. I was told I probably had fibromyalgia and that “some people are just more prone to respiratory infections; here’s another antibiotic.” I requested allergy tests and blood tests multiple times only to be told my results were normal. I even requested a sleep study, as I knew I was not getting quality, restorative sleep. When the results came back, I cried when they told me I had sleep apnea; I finally had an answer to my mystery illness! But my elation didn’t last. A few minutes later, they told me they had grabbed the wrong file and read me someone else’s diagnosis. Naturally, I cried again, as I was back to zero answers. Although no doctor ever verbalized it, I began to wonder if all my problems were psychological. I began to feel I couldn’t trust my own judgment about anything.

Trudie: How were you finally diagnosed?
Tami: Shortly after the sleep study, I visited my fairly new primary care physician with my third sinus/respiratory infection in the short six months that I had been her patient. She wrote another prescription for me, but then also wrote something down and handed it to me saying, “I want you to get in as soon as possible to see this specialist.” Gratefully, she was my advocate at a time when I was too sick to be my own. I saw my specialist and immediately began the testing to verify his hypothesis of a primary immunodeficiency disease. When he delivered the official diagnosis, he was so calm when he said “common variable immune deficiency.” So, of course, I assumed he would tell me how this disease would be cured, because my ears heard it was “common.” Although I was immensely relieved to have a label for my long-term illness, it wasn’t until about one year into treatment that I finally began to grieve what it all meant and how it would change my life permanently.

Trudie: What is your treatment plan now?
Tami: I am now doing subcutaneous immune globulin therapy once a week. I have been doing it for three years now. Each year, my health is getting better.

Trudie: How did your healthcare plan differ while living in Europe?
Tami: My husband is native to the
Netherlands, and we wanted to have time with his family and for our son to learn about this part of his heritage. I appreciate so many things about the Dutch culture and their approach to health, and I even appreciate the fact that they don’t overuse antibiotics. However, living there was a bit challenging for me to manage a disease that is dependent upon occasional antibiotics. We had to order my antibiotic (a very common one in the U.S.) through an international pharmacy. I do miss the quality of life in the Netherlands that comes from 40 vacation days a year; I think that is a pretty good formula for good health!

Trudie: How has CVID changed your life?

Tami: I was diagnosed when our only child was 3 years old, and the fact that there is a genetic component encouraged me to make the decision to not have more children. I also had been a serious runner for 25 years, running 5Ks, 10Ks, half marathons and a marathon in 2003. The week after the marathon, I felt my body telling me to stop exercising completely and to give up my long-time running passion. That’s when I knew there was really something wrong with me. On the positive side, CVID has taught me to respect my body’s limitations and that it’s OK to nap. I have learned that some exercise is better than no exercise, and that I don’t have to be in marathon shape to be strong and healthy. I have also begun enjoying exercises I had never tried before, like yoga and Pilates, which have great benefits all around. And, I have learned to enjoy and be present in the moment. I’m not always good at it, but my son is a wonderful reminder of how great life is in the here and now.

Trudie: What are some of your dreams and goals?

Tami: I do still have the goal of running races again. Maybe not a marathon; I’d be happy with a half! Most of all, I want to have consistent energy and strength to be able to participate in sports with our son who loves being active!

Trudie: What has chronic illness taught you about yourself?

Tami: I’ve learned to trust my instincts, even after 20 years of others telling me nothing was wrong with my health. And also to not let chronic illness become my identity. I am much more than just one aspect of my life.

Trudie: What advice do you have for other patients?

Tami: Those of us with chronic illness can’t undo the illness, but we can learn to adapt and, in the process, stumble across something new to enjoy. Someone once told me there is opportunity that comes out of crisis. On my challenging days, I try to remember that it’s leading me up to a new opportunity and to keep my mind open about the definition of opportunity.

That is the definition of opportunity.

If your life depends on immune globulin and you have a unique experience to share, we want to feature you in this column! Email us at editor@IGLiving.com.

TRUDIE MITSCHANG is a staff writer for IG Living magazine.

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One Sick Mama
By Ever Fecske Mazza

MOTHERHOOD IS complicated! With eating schedules, sleep training and tummy time, there are so many questions and doubts. “Should I always follow my instincts?” “Are all of these mommy blogs good for my mental state?” (The answer to that is no!) “Does my baby’s tummy hurt?” “Why is he snoring?” “Should I prop his head up?” “Is that spit up or throw up?” “Wow, that was a short nap!” “I really have to pee; do I bring him with me?” Every parent is faced with fears about this enormous responsibility. But, then there are those questions only we have. “Is he sick because he has CVID or some other immune-related disorder?” “Should I get him tested now?” “How do I stay away from him when I’m sick?” “Or, when he is sick?” The questions never end, and it makes parenthood tougher.

I wanted to be a mother like I’ve never wanted anything before. I feel thankful every day when I look at my sweet baby — even when he is covered in food or that awful moment when I think it may be poop! I wouldn’t trade it for anything. I would even take prednisone for him — and that’s huge!

I find it strange that for the first time in my life, I have no idea if I am doing the right thing. But, I tell myself that I must be doing something right when I see him growing and changing faster than I can change his diaper. Wait, I thought we were just getting the hang of sitting up; now you want to crawl? Wait for me…. I’m only just grazing the surface here. I hear rumors about when my little guy starts school: “Oh just wait! You are going to be sick for a good three years straight!” Um, excuse me? That’s enough to scare the heck out of me! Since Boston was born, I have been sick five times with either a sinus infection or bronchitis. Not to mention that I had to stop nursing him at 5 weeks old because I was fighting the worst urinary tract infection imaginable and had to be admitted for IV antibiotics. So, that’s six-plus infections in 10 months.

What does a mama do when she is sick all the time? Three rounds of antibiotics later, and I still can’t kiss my baby goodnight. It’s the most helpless feeling on top of feeling guilty that I have not been able to give him 100 percent of me. I see that he needs me to snuggle and play, and I have to admit sometimes I do, and then I feel guilty about that. I need to be there for him when he wakes up during the night, which means interrupted sleep for me. And, we all know that good sleep is a key factor in getting well.

As if this isn’t enough, I never even considered the fact that we would be passing our germs back and forth. He has been sick three times: once with a cold, once with an upper-respiratory infection and once with an ear infection. He has had a chest X-ray and one round of antibiotics, and I am not proud to say that he has already had his first dose of prednisone. (On a side note, can I just tell you that a baby on prednisone is 100 times worse than I could have ever imagined. Non-stop crying! The prednisone monster got him!)

I decided to ask my doctor if she had any advice for dealing with being sick all the time while caring for my baby. She just looked at me blankly and said something along the lines of: “It’s just one of those things you have to deal with.” Really? That’s it? Upon leaving her office, it dawned on me that this is going to be one of my new struggles, a struggle that I never even thought about. I have to do everything I can to get well and stay that way. Before baby, being sick was inconvenient. After baby, being sick is the ultimate challenge to juggle my needs with the needs of the person who relies on me the most.

So, as I discover the way on my own, I plan on enjoying every moment — from the dance parties we have before bed and even the poop that mysteriously seems to get everywhere. We are learning together.

EVER FECESKE MAZZA was diagnosed with CVID and interstitial lung disease in 2004. She is a new mom of a sweet little boy named Boston, and loves every minute of it! She lives in Los Angeles, Calif., with her husband, and when she isn’t changing diapers and playing with her son, she enjoys wedding planning, baking, flower arranging, cooking, shopping and anything that sparkles!
Life as a 20-Something

The Elevator Pitch: How to Quickly Explain Your Disease

By Ilana Jacqueline

THERE HAVE BEEN far too many embarrassing moments in my life when I’ve had to introduce myself and then my disease in the same breath. Quickly summing up primary immunodeficiency disease (let alone the other illnesses I’ve been diagnosed with) in one breath would take some Olympic lungs that I just don’t have. That’s where the “elevator pitch” comes in. There are so many situations in your 20s where you’ll need to use an elevator pitch to describe your disease. Between job interviews, first dates, new friends, even professors who will need to get the SparkNotes version of your disease in between classes, an elevator pitch may end up being one of your greatest tools when it comes to advocating for your needs.

Here are some tips on perfecting your pitch quickly, accurately and without getting that blank stare in return:

Ask before you explain. It’s rare, but sometimes people have actually heard of your disease and don’t even need to hear your spiel. So, before breaking into song and dance, preface your pitch by saying: “I have a disease called primary immune deficiency. Are you familiar with it?” This statement actually accomplishes two things: It verifies whether someone knows what your disease is, and it gives them the option of asking for more information if they don’t.

Don’t get too technical. Instead of focusing on the pathology of your disease, focus more on how the disease affects you as a person. You may want to say that because of this disease, you’re more susceptible to infection, so you might have to be more cautious than the average person. You may also want to say that your body doesn’t produce the natural defenses against infection, so you have to have medication to replace it. Or, that some days, you feel completely normal and can function just like everyone else, and some days, you feel like you got hit by a train.

Use analogies. Relate your disease to something the person will understand. This can be altered when you’re speaking to children, adults and even doctors who are unfamiliar with your condition. People with Crohn’s disease might say something like: “Living with Crohn’s is like carrying around a ticking time bomb. One wrong bite could set off a painful stomach ache that can knock me out for the rest of the day or week.” I’ve heard others describe immune disorders as “being the only one casually walking through a war zone every day without any armor on — and then people are shocked and confused when you get a few bullet holes in your chest.”

Mention what it doesn’t affect. Don’t forget to tell inquiring minds what you still can do — despite your disease. Mention if you can still work, go to school, go out for a few hours a day, or see and communicate with your friends online or over the phone. This helps to remove yourself from the pity equation and includes them in some of these parts of your life.

Keep it short, and shut it down. The whole point of an elevator pitch is to avoid long-winded (and often depressing) conversation about your disease. So, keep your explanation short and to the point: This is what I have, this is how it works, now let’s go get some tacos. A good way to bring the conversation to a screeching halt is to say something like: “It’s kind of complicated, but I hope that explained some of it. You can always Google it later if you want to get a better idea of what it is.”

Remember that the way you discuss your disease is the way others will interpret it. If you give a humorless, depressing description of your disease, you’ll inevitably bum your audience out. So, don’t be afraid to have fun with it. For instance, you could finish your speech by gently grasping their shoulder and saying: “…and it’s highly, highly contagious.” Just kidding!

ILANA JACQUELINE is a 23-year-old 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.
Are Sports Safe for PIDD Kids?

By Mark T. Haggard

As a coach, I have found that sports are one of the best ways to help adolescent students develop their bodies physically and mentally. Sports help them to build self-confidence and to assimilate into the school community. Yet, with all of the positive aspects associated with sports, some parents believe there are reasons why kids with primary immunodeficiency disease (PIDD) should not get out and play. But, while their concerns are valid, the benefits of sports far outweigh the risks.

Social Benefits of Sports

No matter how hard schools try to break down barriers between cliques, these barriers still exist. Students can be quite cruel to other students who appear to be outsiders or weaker than they are. Unfortunately, in many cases, PIDD kids are on the outside looking in. These children have had numerous illnesses that cause them to miss school days and make it more difficult to socialize. But, sports allow these students to find a place in the school community. In fact, many PIDD kids I have interviewed over the years spoke of being picked on before joining a team. Once they joined, they experienced an immediate entry into a safe place within the school community.

Physical Benefits of Sports

Obviously, there are benefits to the intense physical activity of high school athletics. Physical activity builds healthy bodies and instills good habits for a lifetime of good health. But, it is not just muscles that are built through sports training. Studies show that physical activity may increase immune response to infections.

One study at the University of South Carolina compared the immune health of participants engaged in at least 30 minutes of moderate exercise with those who did no exercise at all. The group that performed moderate exercise on most days averaged one cold during the year, whereas those in the less-active group reported four colds over the course of the year. A similar study at Appalachian State University found that students who walked regularly and still got colds recovered in fewer than five days, whereas those who did not walk took seven days to recover.

Infection Hazards of Specific Sports

Which sports PIDD kids should and should not engage in can be evaluated by the risk of infection. There are two sources of potential infection: 1) wounds caused by repeated cuts and scrapes, and 2) an environment where germs and bacteria are more prominent. The potential for wounds depends on the intensity of contact by participants. In collision sports such as football, rugby and hockey, players run into and bounce off of each other, providing the highest potential for open wounds and, thus, opportunities for infection. With contact sports like basketball, water polo and soccer, there is only an occasional collision and, therefore, less opportunity for cuts and scrapes. The exception here, however, is wrestling. While wrestling is a great contact sport for adolescents with healthy immune systems, the continual body contact and constant contact with the
wrestling mat provide an environment rife with staph infections. Non-contact sports such as golf, bowling, track, cross country, swimming and volleyball are the least risky because they put athletes on the opposite sides of the playing field or on the field at different times.

Sports played in an outside environment on dirt or grass are the most likely to cause infections in PIDD kids. Indoor sports, on the other hand, offer a cleaner environment. With the amount of cleaning agents used, the pool is likely the safest place for PIDD kids.

Table 1 depicts how potentially hazardous a sport may be for PIDD kids’ immune systems. For instance, football and rugby (collision sports played on grass and dirt) pose the most potential infection hazard, while swimming and diving (non-contact sports played in the pool) pose an almost insignificant infection hazard.

### Table 1. Infection Hazards in Sports

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<tr>
<th>Level of Contact</th>
<th>Outdoor (high risk)</th>
<th>Indoor (moderate risk)</th>
<th>Water (low risk)</th>
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<tr>
<td>Collision (high risk)</td>
<td>Football</td>
<td>Hockey</td>
<td>Water Polo</td>
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<td>Rugby</td>
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<td>Contact (moderate risk)</td>
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<td>Lacrosse</td>
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<td>Non-Contact (low risk)</td>
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<td>Cross Country</td>
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The Haggard Experience

My son, Caleb, played football his last year of junior high school and is playing this year as a high school freshman. I kept him away from football until he was in eighth grade, not because of PIDD, but because of the potential damage he could do to his growing body. In his two years of playing football, he has not had any infection that I can attribute to the sport. Instead, the training regimen for football has been great for his immune health.

The only interruption to Caleb’s season was an overnight hospital appointment. It is best not to leave coaches in the dark about hospital appointments during the season and in the off-season. Coaches should also be alerted to fatigue brought on by infusions. We rescheduled Caleb’s infusions around practice so that next-day fatigue did not interfere with the intensity needed for practice.

Having a condition in which even the slightest wounding of a child’s body might cause an infection may cause some trepidation for parents. But, sports provide them a great opportunity. It allows them to better socialize in the school setting, helps to boost their immune systems, and teaches self-confidence, sacrifice and loyalty. As parents of PIDD kids, we should not use their disease as an excuse to keep them from doing something they enjoy.

MARK T. HAGGARD is a high school teacher and football coach, and has three children, two of whom have CVID. He and his wife, Cheryl, also operate Under the Hood Ministries at www.underthehoodministries.org.

### References

IT’S MY BIG day. The food, entertainment, finances and, of course, the wonderful people who surround me are ready to make sure my big day goes off without a hitch. And, in what seems to be a whirlwind of details, my big day finally arrives and not a minute too soon: Stress from all the “i” dotting and “t” crossing has invaded my compromised immune system and, like clockwork, a virus threatens to ruin all of my hard work. Energy waxes and stress wanes as my anticipated moment finally arrives. I’ve made it to my big day: my infusion day.

OK, so I might be being a bit over-dramatic, but can you spot me a few points for being creative? I’ve been through hundreds of big (infusion) days between my son, Caleb, my daughter, Molly, and my father, Doug (who passed away three years ago due to complications of common variable immune deficiency). With all the IV pokes and infusion reactions—unrelenting nausea, vomiting, piercing migraine headaches and assorted post-infusion nightmares—I must learn to embrace my infusion day.

How do I do this, you ask? ‘Tis not an easy task, m’friend. Prepping two toddlers for adult-sized medical procedures isn’t exactly going to the Seychelles. It all started with packing the picnic basket full of toddler-friendly/IV-bribing foods. As the kids got older, they wised up to what the picnic basket was really about. Our family picnics looked nothing like the opening scene of “The Sound of Music” in which Maria croons how the hills are alive. No, those early intravenous immune globulin (IVIG) days were more like the infusion suite at Children’s Hospital is alive with the sounds of Haggard children protesting, in a rather earsplitting manner, their pending IV pokes. There weren’t enough performing purple dinosaurs on public television that could distract my rather raucous rugrats from having IVs inserted in their hands and feet. The one mantra that kept us from running toward the hills, desperately looking for Ms. Andrews, was knowing the IG was—and still is—keeping our family intact.

Because my family is genetically challenged, I wasn’t completely shocked when the aches and pains that autoimmune disease inflicts came knocking on my blood cells’ doors. When it came my turn to
experience my big (infusion) day, fear struck a nostalgic chord in my memory bank. It became so obnoxious that I demanded a recount of my blood draw, and I insisted the lab switched my IG levels with someone else’s.

“Are you sure that IgM number reads 133 and not 331?” I nagged my infusion nurse, D’Angela. Even my last-minute pleas fell on deaf ears. “You can do this, Cheryl! So, let’s get you on the books,” D’Angela cheered while she turned the page of the infusion center’s master calendar. “So, how does tomorrow look?”

My joints, muscles and even my eyebrows screamed “take the appointment!” However, I think the stiffness that comes with my autoimmune disease officially reached my brain.

“How about we get you on the books? Let’s get you on the books,” D’Angela gave me one of those nurse-y looks and then cooed: “Cheryl, it’s six hours that will inevitably change your quality of life. So how’s nine in the morning working for ya’?”

I looked at the director of nurses, Anne, and mouthed, “Did she just say six hours?”

Anne nodded her head up and down enthusiastically and stepped around her desk to where I was trying to not pass out.

“Awwww,” Anne cooed sympathetically. “It’ll be the best six hours of your week. You’ll see.”

My big day had arrived, and it truly felt like my wedding day, the first day of my first teaching job and giving birth — all three at the same time. My insides were flip-flopping, my heart was pounding and my brain was spinning.

“Come sit over here,” D’Angela said, motioning to an overstuffed, chocolate brown leather La-Z-Boy.

I took mental inventory of the infusion suite I’d be assigned and concluded like Dorothy in the “Wizard of Oz”: “I’m not at Children’s Hospital anymore.” A basket of toothsome treats were within arm’s reach from where I sat in the yummy comfy recliner. A slight hand movement to the north, I now held a remote to my “will-not-need-to-be-shared” 56-inch plasma TV. Within eyeshot to the south, my very own stocked mini fridge hummed in the corner, cooling all my favorites to the perfect temperature. And, dangling from my IV pole: a life-alert type device just in case I needed someone. The one thing missing was another patient.

“OK, Cheryl. D’Angela will be here in a minute to get your IV started and then get your infusion dripin’,” Zoe, a nurse’s assistant, interrupted my blessed Nirvana. “Under your remote is the menu. Just press the button on the IV pole and let me know when you’re ready to order. OK, then, well … bye!” Zoe closed the door behind her and I basked in the utter silent of silence.

I thought I was dreaming until I heard D’Angela’s voice whispering: “It’s IV time, Ms. Haggard.”

“D’Angela, I have terrible veins, so please know I won’t be shocked if you have to go after my veins a dozen times before you…."

“Cheryl,” D’Angela said, tenderly turning away my tattling. “I want you to take a gradual, deep breath and then on my count, let it go gently.” I nodded in agreement, drew air from what felt like my toes and by the time she counted to five, the IV was placed and, miraculously, I wasn’t a human pincushion.

Five-and-a-half blissful hours later, I had a nap, watched my favorite TV show without interruption, noshed on a gourmet sandwich from a highly sought-after lunch spot (the delivery guy wasn’t too difficult to look at, either!) and savored a sweet treat from my personal snack basket. After I took a potty break — sans note from one of my kids shoved under the bathroom door asking if she could go to her best friend’s house — I decided an ice cold Frappuccino from the fridge fit the moment and was the perfect way to top off my big day.

Two-and-a-half years later, I’m still enjoying the first-class service I received on my first big day. So, when people ask me how I cope with infusion days, recalling how difficult it was for us before Caleb and Molly switched to homecare/subcutaneous infusions seven years ago, I nonchalantly respond with: “I will most likely take a much-needed nap, watch some TV and even use the bathroom in peace.”

“And the food?” they ask. “Isn’t hospital food awful?”

“The food is the best part!” I respond with a twinkle in my eye. Remember that cute delivery boy from the swanky lunch spot? Well, he’s been replaced by my not-so-difficult-to-look-at husband, Mark. Now, that’s how I embrace my big day!

CHERYL L. HAGGARD is a stay-at-home mom and has three children, two of whom have CVID. She and her husband, Mark, also operate Under the Hood Ministries at www.underthehoodministries.org.
IG Chronicles

Needles & Spines

By Rebecca Zook

In the summer of 2008, Rebecca Zook was diagnosed with common variable immune deficiency. She receives infusions of IgG antibodies every three weeks and encourages everyone to donate plasma from which this lifesaving medicine is derived.

THE AMBIENT SOUNDS in the large tiled room suddenly cease. Everyone is listening. At first you can barely make out the whistling, but soon smiles can be seen on most of the patients sitting in the turquoise chairs. Even some toe-tapping. The tune is familiar to everyone. Someone at the far end of the room is watching “The Andy Griffin Show.” As the last note fades, the voices regain strength. More people arrive to fill the chairs. The smiles, however brief, are welcome and needed. Most of the people sitting in the chairs are quietly engaged in battle. Most are fighting cancer.

Often the first one here, I always sit by the window. There are roses outside in warmer months. My feet dangle in the chair, not quite reaching the floor. My shoes slip off. I feel a bit like a child here — dependent on the staff that bustles around reacting with efficiency to the beeping of the machines calling out to them. Would I like a blanket, a pillow? Something to eat?

No, I’m fine. I’m here once every three weeks. It provides me with a unique perspective about people and about life. I have a treatable, but not curable blood disorder, a primary immune deficiency. Intravenous immune globulin (IVIG), an expensive blood plasma product, boosts my immune system and helps to control secondary autoimmune diseases. It’s also the only treatment available for my illness.

We are hooked up to individual machines. Mine is giving me infection-fighting antibodies. Theirs essentially pumping poison into their bodies to kill invading cells. A man comforts his wife, talking in quiet whispers. It’s only her second time here. Some patients just want to sleep during their treatment. Others are compelled to talk, desperate to make a connection with someone who understands. I’ve heard about all types of cancers here. Of people’s marriages breaking up while they are still sick. Right now, the man next to me is discussing a dog that recently came into his life. He didn’t want it. He thought he hated dogs. Now he is grateful for its affection and that it has given him something to focus on other than his cancer.

In some ways, I feel like a fraud being here. I’ve been asked more than once what kind of cancer I have, and I actually feel bad explaining that I don’t have it. I also envy these people. They have a shot at getting better, of never setting foot in here again. This is a life sentence for me. Every three weeks, forever, hoping that my veins hold out, but self-pity is not something to cling to.

There is another group of people who come here. I wonder at their life story, but I can’t speak with them. Hands and feet in shackles flanked in front and rear by armed guards. All heads turn as they are marched through the room and placed in their own section. For a minute, the rest of us forget about our struggles. They are the incarcerated, the prisoners, also here for treatment. I imagine the trip and time here is something they look forward to. I imagine it’s better than day after day in a cell.

A sign on the wall proclaims: “Live. Laugh. Love.” We all deal with our personal disease differently. Some are overcome with sadness or anger. Some pray. Others are stoic and practical, realistic about the odds. But we are all trying. All of us. We understand more than most that each day is a gift not to be wasted.

REBECCA ZOOK is an award-winning artist and writer.

This blog is reprinted with permission from Rebecca Zook’s blog at rebeccazook.blogspot.com. This blog also appeared on IG Living’s blog on April 11, 2013, at www.IGLiving.com/blogengine.

Patients who rely on IG therapy have unique life experiences. If you have a story you’d like to share about your adventures, experiences, relationships, reminiscences, self-portrayals, etc., for publication in this column, submit it to editor@igliving.com. All submissions must be 600 words or fewer and can be accompanied by high-resolution photos.
**Historical Perspectives in the Diagnosis and Treatment of Primary Immune Deficiencies**

Author: Mark Ballow  
Publisher: Critical Reviews in Allergy & Immunology, Springer US, link.springer.com/article/10.1007%2Fs12016-013-8384-9#

The field of primary immune deficiency disorders (PIDDs) has advanced rapidly over the past several years with more than 200 different gene mutations defined. With the recent institution of newborn screening for T cell deficiencies in many states and earlier recognition of the signs and symptoms of patients with immune deficiency, it is now apparent that PIDD is not as “rare” as was originally thought several decades ago. With the earlier recognition of patients with recurrent infections and various immune perturbations, advancements in the treatment of these immune deficiency disorders have led to enhanced survival and quality of life. In this issue, the diagnosis of PIDD through laboratory testing and skin manifestations is reviewed. The more recently described cellular immune deficiencies, selective immune deficiencies, and advances in the use of bone marrow transplantation in the correction of some of these immune deficiencies are discussed.

**In the Kingdom of the Sick: A Social History of Chronic Illness in America**

Author: Laurie Edwards  

More than 133 million Americans live with chronic illness, accounting for nearly three-quarters of all healthcare dollars, and untold pain and disability. There has been an alarming rise in illnesses that defy diagnosis through clinical tests or have no known cure. Millions of people, especially women, with illnesses such as irritable bowel syndrome, chronic pain and chronic fatigue syndrome face skepticism from physicians and the public alike. Through research and patient narratives, health writer Laurie Edwards explores patient rights, the role of social media in medical advocacy, the origins of our attitudes about chronic illness and much more. According to reviews, what *The Noonday Demon* did for people suffering from depression, *In the Kingdom of the Sick* does for those who are chronically ill.

**Talking to Your Doctor: A Patient’s Guide to Communication in the Exam Room and Beyond**

Author: Zackary Berger  

*Talking to Your Doctor* helps readers navigate the new, more promising waters of doctor-patient collaboration, starting at the simplest and most human interaction — the conversation between two people in a room — and ending with the benefits that can be obtained by cultivating an effective partnership. While patients need to take control of the visit and set their agenda, the latest research shows that doctors and patients need to connect on a more emotional level as well. In this book, readers will: learn how to talk to their doctor and get their doctor to talk to them; discover the science of doctor-patient communication and its relevance to the lay public; remake the relationship with a doctor and the healthcare system on the basis of good communication; make sure the visit with the doctor is productive and meets patients’ needs; and help patients and others avoid over-testing and over-treatment. The book explains how starting with the conversation can redress imbalances and put the relationship of doctor and patient, and eventually the entire healthcare system, back on a healthy footing. Using illuminating model dialogues, real transcripts from the clinic and hospital, resources for communication improvement, and a brief history of doctor-patient communication, the author helps readers develop strategies for obtaining better care from their doctors, from the minute they step into the exam room.
Sources

Summer Camp Checklists
By Carla Schick

SUMMER CAMP HAS many benefits for all children, especially those in the immune globulin (IG) community. Staying at specialized camps that cater to children with serious illnesses can help build self-confidence, foster self-reliance and give them the opportunity to form lasting friendships with others who are dealing with similar health issues. But, when it comes to sending IG-treated children off to summer camp, packing the right gear is vital to ensuring an enjoyable camp experience. Here are a few suggestions.

Clothing

Some camps require campers to bring a sweater, jacket and rain poncho in preparation for inclement weather. But, instead of sending multiple pieces of outerwear, try packing a lightweight, waterproof jacket. The thinner fabric makes it easy to pack and can be worn in various climates. If cold weather is expected, long pants or jeans and long sleeve shirts are necessary.

Also, pack at least one pair of sturdy closed-toed shoes. Some camps advise bringing a second pair of comfortable shoes in case the first pair becomes soiled or lost. Tennis shoes are a popular choice since they are supportive, lightweight and make for good multi-activity footwear. And, don’t forget to pack a few pairs of comfy socks as well.

If children are attending camp in a warmer climate, make sure they bring shorts and short sleeve shirts along with a hat and sunglasses. Swimsuits are also a must-have clothing item if swimming or other water sports are on the activity list. Additional clothing essentials include several pairs of underwear and at least one set of pajamas.

Essentials and Comforts

Occasionally, children become homesick. This can be remedied by packing favorite toys, books, music or other reminders of home such as photos.

Campers may be required to bring personal necessities. For instance, some camps do not provide towels, washcloths, blankets or pillows, so double check with the camp before packing to see whether these items are needed. An alternative to sending both a blanket and pillow is to send a sleeping bag. They are warm, compact and easier to pack.

Other essentials include sunscreen, soap, bug spray, toothpaste and toothbrush, deodorant, a hair brush, and feminine hygiene products for girls. It is also wise to pack a flashlight, backpack, water bottle and swim goggles.

Medication

Perhaps the most important elements to pack for IG-treated children are medications and medical supplies. If children receive subcutaneous IG infusions, make sure to pack their infusion pump, butterfly needles, syringes, sharps container, alcohol wipes and properly stored IG.

Anaben Kazemi, IG Living’s patient advocate, also recommends packing additional provisions that can make children feel more relaxed, namely pain medication, a hot water bottle, rub and Epsom salts for aches and pains, a special head or neck pillow, and a medical journal or infusion log to keep track of symptoms and treatments. Also, remember to include enough medication for the number of days children will be away from home, to label all medications and supplies with the children’s names, and to include a list of medications and their dosage and treatment schedules.

Just Have Fun!

Of course, the most important thing to remember is to have fun! The late actor Paul Newman, who founded The Hole in the Wall Gang Camp, said that his mission was to create a “community that celebrates fun, friendship and spirit of childhood where every kid can ‘raise a little hell.’”

CARLA SCHICK is a staff writer for IG Living magazine.

Sources

The Hole in the Wall Gang Camp
The Hole in the Wall Gang Camp is located in Ashford, Conn. Each summer, the camp offers a variety of programs that cater to seriously ill children and their families, completely free of charge. A special summer session for children with immunology issues will be held July 2 through 8.
(860) 429-3444, www.holeinthewallgang.org

The Painted Turtle
The Painted Turtle is a camp funded by the late Paul Newman. Located in Lancaster, Calif., it entertains children with chronic health conditions and their families free of charge. The primary immunodeficiency disease (PIDD) summer session will be held from Aug. 6 through 10, and the PIDD family fall weekend will be held Sep. 26 through 28.
(661) 724-1550, www.thepaintedturtle.org

Victory Junction Gang
The Victory Junction Gang is located in Randleman, N.C., and is also a member of the SeriousFun Network founded by Paul Newman. During the summer, the camp offers disease-specific sessions at no cost to campers and their families. Their special Wet and Wild Week for Cancer, Diabetes and Immunology will be held from June 22 to 26.
(336) 498-9055, www.victoryjunction.org

Double H Ranch
The Double H Ranch is located in New York’s Adirondack Park in Lake Luzerne. From June through August, the camp features eight Summer Residential Camps for critically ill children between the ages of 6 and 16 and their families. The six-day camp sessions are free of charge and include an offsite visit to their local amusement park, Six Flags Great Escape.
(518) 696-5676, www.doublehranch.org

Camp Prime Time
Camp Prime Time is located in Yakima, Wash., and offers seriously ill children and their families the ability to experience the great outdoors of the Pacific Northwest at no charge. The Immune Deficiency Foundation is listed as a support group that currently participates in prime time programs.
(509) 248-2854, www.campprimetime.org

Immune Deficiency Foundation Retreats
The Immune Deficiency Foundation offers retreats for everyone in the primary immunodeficiency community, including patients and their parents. The retreats give participants the opportunity to connect with others and to learn more about their condition from leading physicians and healthcare professionals. Two retreats will be held in 2014. The first will be in Atlanta, Ga., from June 20 to 22, and the second will be held in Portland, Ore., from Sep. 5 to 7.
(800) 296-4433, www.primaryimmune.org
Sources

For a more comprehensive list of resources, visit the Resources page at www.IGLiving.com.

General Resources

These organizations provide information about various disease states, which can be found by conducting a search of the disease state name.

- Advocacy for Patients with Chronic Illness: www.advocacyforpatients.org
- American Autoimmune Related Diseases Association (AARDA): www.aarda.org
- American Chronic Pain Association (ACPA): www.theacpa.org
- Band-Aides and Blackboards: www.lehman.cuny.edu/faculty/jfleitas/bandaides
- eMedicine from WebMD: emedicine.medscape.com
- FamilyDoctor.org: www.familydoctor.org
- Johns Hopkins Medicine: www.hopkinsmedicine.org
- KeepKidsHealthy.com (pediatrician’s guide to children health and safety): www.keepkidshealthy.com
- Mayo Clinic: www.mayoclinic.com
- National Committee for Quality Assurance (detailed report cards on health plans, clinical performance, member satisfaction and access to care): www.ncqa.org
- National Heart, Lung and Blood Institute: www.nhlbi.nih.gov/health/health-topics/by-alpha
- National Institutes of Health: health.nih.gov/see-all-topics.aspx
- National Organization for Rare Disorders (disease-specific support groups and virtual communities for patients and caregivers): www.rarediseases.org
- Office of Rare Diseases Research: rarediseases.info.nih.gov
- Patient Advocate Foundation (patient access to care, maintenance of employment and financial stability): www.patientadvocate.org
- WebMD (medical reference): www.webmd.com

IG Manufacturer Websites

- Baxter: www.baxter.com
- Bio Products Laboratory: www.gammplex.com
- CSL Behring: www.cslbehring.com
- Grifols: www.grifolsusa.com
- Kedrion: www.kedrionusa.com
- Octapharma: www.octapharma.com

Disease-State Resources

Ataxia Telangiectasia (A-T)

WEBSITES
- A-T Children’s Project: www.atcp.org

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

WEBSITES
- GBSCIDP Foundation International: www.gbs-cidp.org
- The Neuropathy Association: www.neuropathy.org

Evans Syndrome

ONLINE PEER SUPPORT
- Evans Syndrome Research and Support Group: www.evanssyndrome.org

Guillain-Barré Syndrome (GBS)

WEBSITES
- GBS/CIDP Foundation International: www.gbs-cidp.org
- The Neuropathy Association: www.neuropathy.org

ONLINE PEER SUPPORT
- GBS Support Group: www.gbs.org.uk
- GBS/CIDP Foundation International Discussion Forums: www.gbs-cidp.org/forums

Idiopathic Thrombocytopenic Purpura (ITP)

WEBSITES
- ITP Support Association — UK: www.itpsupport.org.uk
- Platelet Disorder Support Association: www.pdsa.org

Kawasaki Disease

WEBSITES
- American Heart Association: www.heart.org/HEARTORG/Conditions/More/CardiovascularConditionsOfChildhood/Kawasaki-Disease_UCM_308777_Article.jsp#.T1T2boePWEO
- Kawasaki Disease Foundation: www.kdfoundation.org

Mitochondrial Disease

WEBSITES
- United Mitochondrial Disease Foundation: www.umdf.org
- MitAction: www.mitaction.org
Multifocal Motor Neuropathy (MMN)

WEBSITES
- The Neuropathy Association: www.neuropathy.org

Multiple Sclerosis (MS)

WEBSITES
- All About Multiple Sclerosis: www.mult-sclerosis.org/index.html
- Multiple Sclerosis Association of America: www.msaa.com
- National Multiple Sclerosis Society: www.nationalmssociety.org

ONLINE PEER SUPPORT
- Friends with MS: www.friendswithms.com
- MSWorld’s Chat and Message Board: www.msworld.org

Myasthenia Gravis (MG)

WEBSITES AND CHAT ROOMS
- Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org

ONLINE PEER SUPPORT
- Genetic Alliance: www.geneticalliance.org

Myositis

WEBSITES
- The Myositis Association: www.myositis.org

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)

WEBSITES
- P.A.N.D.A.S. Network: pandasnetwork.org

Pemphigus and Pemphigoid

WEBSITES
- The International Pemphigus and Pemphigoid Foundation: www.pemphigus.org

Peripheral Neuropathy (PN)

WEBSITES
- Neuropathy Action Foundation: www.neuropathyaction.org
- International Myositis Assessment and Clinical Studies Group: www.niehs.nih.gov/research/resources/collab/imacs/main.cfm

ONLINE PEER SUPPORT
- Michigan Immunodeficiency Foundation: www.facebook.com/groups/108048062584350
- Myositis Association Community Forum: tmacommunityforum.ning.com
- Myositis Support Group: www.myositisupportgroup.org
- Myositis Support Group – UK: www.myositis.org.uk

Primary Immune Deficiency Disease (PIDD)

WEBSITES
- The National Institute of Child Health and Human Development (NICHD): www.nichd.nih.gov/health/topics/Primary_Immunodeficiency.cfm
- American Academy of Allergy, Asthma & Immunology: www.aaaai.org
- International Patient Organisation for Primary Immunodeficiencies (IPOPI) — UK: www.ipopi.org
- New England Primary Immunodeficiency Network: www.nepin.org

The Neupathy Association, www.neuropathy.org, is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association’s mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, and advocate the need for early intervention and support research into the causes and treatment of neuropathies.

(212) 692-0662

The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

(800) 296-4433

The Jeffrey Modell Foundation, www.info4pi.org, is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency.

(212) 819-0200
Sources

- **Rainbow Allergy-Immunology:**
  [www.uhospitals.org/rainbow/services/allergy-immunology](http://www.uhospitals.org/rainbow/services/allergy-immunology)

- **Team Hope (for families and patients in New England):**
  [www.teamhope.info](http://www.teamhope.info)

### Online Peer Support

- **IDF Common Ground:**
  [www.idffriends.org](http://www.idffriends.org)

- **IDF Discussion Forum:**
  [http://idffriends.org/forum](http://idffriends.org/forum)

- **IDF Friends:**
  [http://idffriends.org](http://idffriends.org)

- **Jeffrey Modell Foundation Message Board:**
  [www.info4pi.org](http://www.info4pi.org)

- **Michigan Immunodeficiency Foundation:**
  [www.facebook.com/groups/108048062584350](http://www.facebook.com/groups/108048062584350)

- **Rhode Island peer group:**
  [health.groups.yahoo.com/group/RhodeIslandPIDD](http://health.groups.yahoo.com/group/RhodeIslandPIDD)

### Scleroderma

#### Websites

- **Scleroderma Foundation:**
  [www.scleroderma.org](http://www.scleroderma.org)

- **Scleroderma Research Foundation:**
  [www.srfcure.org](http://www.srfcure.org)

- **Scleroderma Center:**
  [www.hopkinsmedicine.org/rheumatology/clinics/scleroderma_center.html](http://www.hopkinsmedicine.org/rheumatology/clinics/scleroderma_center.html)

#### Online Peer Support

- **Scleroderma Support Forum:**

### Education and Disability Resources

- **Americans with Disabilities Act of 1990:**
  [www ada.gov](http://www ada.gov)

- **Continuation of Health Coverage — Consolidated Omnibus Budget Reconciliation Act (COBRA):**
  [www.dol.gov/dol/topic/health-plans/cobra.htm](http://www.dol.gov/dol/topic/health-plans/cobra.htm)

- **Disability.gov:**

- **Individuals with Disabilities Education Improvement Act of 2004:**
  [idea.ed.gov/explore/home](http://idea.ed.gov/explore/home)

- **National Disability Rights Network:**
  [www.ndrn.org](http://www.ndrn.org)

- **National Heart, Lung and Blood Institute:**

- **Social Security:**
  [www.ssa.gov/disability](http://www.ssa.gov/disability)

- **U.S. Department of Education Website:**
  [www2.ed.gov/parents/landing.jhtml?exp=4](http://www2.ed.gov/parents/landing.jhtml?exp=4)

- **U.S. Department of Health and Human Services, Office of Civil Rights:**

### Other Resources

#### Medical Research Studies

- **ClinicalTrials.com:**
  [www.clinicaltrials.com](http://www.clinicaltrials.com)

- **ClinicalTrials.gov:**
  [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

- **Food Allergy and Anaphylaxis Network:**
  [www.foodallergy.org](http://www.foodallergy.org)

- **National Institutes of Health, National Institute of Allergy and Infectious Diseases (2004). Food Allergy:**
  [www.niaid.nih.gov/topics/foodallergy/Pages/default.aspx](http://www.niaid.nih.gov/topics/foodallergy/Pages/default.aspx)

  [www.worldallergy.org](http://www.worldallergy.org)

#### Product Information

- **Influenza and the influenza vaccine:**
  [www.cdc.gov/flu or call (800) CDC-INFO: (800) 232-4636](http://www.cdc.gov/flu)

- **IVIG Carimune NF:**

- **IVIG Flebogamma 5% DIF and 10% DIF:**

- **IVIG/SCIG Gammagard Liquid:**
  [www.gammagardliquid.com](http://www.gammagardliquid.com)

- **IVIG Gammagard S/D:**
  [www.baxter.com/patients_and_caregivers/products/gammagard_sd_5.html](http://www.baxter.com/patients_and_caregivers/products/gammagard_sd_5.html)

- **IVIG/SCIG Gammaked:**
  [www.gammaked.com](http://www.gammaked.com)

- **IVIG Gammaplex:**
  [www.gammaplex.com](http://www.gammaplex.com)

- **IVIG Gamunex-C:**

- **IVIG Octagam:**

- **IVIG Privigen:**
  [www.privigen.com](http://www.privigen.com)

- **SCIG Hizentra:**
  [www.hizentra.com](http://www.hizentra.com)

#### Pump and Infusion Sets Websites

- **EMED Technologies:**
  [www.emedtc.com](http://www.emedtc.com)

- **Marcal Medical Inc.:**
  [www.marcalmedical.com](http://www.marcalmedical.com)

- **Intra Pump Infusion Systems:**
  [www.intrapump.com](http://www.intrapump.com)

- **Micrel Medical Devices:**
  [www.micrelmed.com](http://www.micrelmed.com)

- **Norfolk Medical:**
  [www.norfolkmedical.com](http://www.norfolkmedical.com)

- **RMS Medical Products:**
  [www.rmsmedicalproducts.com](http://www.rmsmedicalproducts.com)

- **Smith Medical:**
  [www.smiths-medical.com/brands/cadd](http://www.smiths-medical.com/brands/cadd)

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