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IMMUNE GLOBULIN COMMUNITY

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New IGL Feature:

Reimbursement

Q&A

Is Your Infusion Clinic
One of the Good Guys?

Sites of Care
Is Home Sweet Home
the Place for You?

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Attending Physician in Immunology
Children's Hospital of Philadelphia

Marc Riedl, MD, MS

Assistant Professor, Department of Medicine
Clinical Immunology and Allergy
UCLA, David Geffen School of Medicine

Publisher

Patrick M. Schmidt

Editor

Kit-Bacon Gressitt

Assistant Editor

Cheryl Brooks

Contributing Editor

Dayna Fladhammer

Copyeditor and Proofing

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Creative Director

Caroline Carlson

Art Director

Allan Bean

Circulation Director

Carrie Craig

Advertising Manager

Alma Morales

Graphic Designers

Allan Bean

Caroline Carlson

Kim Kinman

Contributing Writers

Pam Barbour

Dan Bennett

Kit-Bacon Gressitt

Cheryl Haggard

Mark Haggard

Ever Fecske

Dayna Fladhammer

Lauren Gerstmann, MPH

Carol K. Miletti

Alma Lucy Morales

Jessica Schulman, PhD, MPH, RD

Melissa Schweitzer

Jeff Siegel

Shirley German Vulpe, EdD

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and marketing communications to
41093 County Center Drive
Temecula, CA 92591
Ph: 800-843-7477 Fax: 951-699-9655
Email: editor@igliving.com
www.igliving.com

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About IG Living

IG Living is the only magazine dedicated to bringing comprehensive healthcare information, immune globulin information, community and reimbursement news, and resources for successful living directly to immune globulin consumers and their healthcare providers.

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Guess What?



All You Have to Do Is Ask

We are very pleased to launch a new IG Living feature in this issue: Reimbursement Q&A on page 23. This column spontaneously evolved from questions about reimbursement we have been receiving from our readers. We're guessing there are a lot more questions out there, and we're eager to do what we can to help.

So, email your reimbursement questions to editor@igliving.com.

The Myositis Association Rocks

On September 25, the U.S. House of Representatives passed House Resolution 974, establishing September 21 as National Myositis Awareness Day. This is a significant achievement in The Myositis Association's campaign to increase awareness of myositis and, ultimately, fund research to find a cure.

Congratulations for a well-run and successful campaign!

We Welcome You to IG Living

We are very pleased to welcome our newest IG Living Advisory Committee members, Jordan Orange, MD, PhD, and Marc Riedl, MD, MS. The two bring stellar qualifications to the task of providing editorial guidance to IG Living.

Dr. Orange is a clinical immunologist, primarily devoted to primary immune deficiencies; he's an attending physician at Children's Hospital in Philadelphia and an assistant professor at the University of Pennsylvania School of Medicine; and, perhaps familiar to many of you, he is chairman of the Primary Immunodeficiency Committee of the American Academy of Allergy, Asthma & Immunology (AAAAI), and was the lead developer of AAAAI's iVIG Tool Kit (<http://www.aaaai.org/members/resources/initiatives/ivig.stm>).

Dr. Riedl is a clinical immunologist and allergist and assistant professor of medicine at UCLA's David Geffen School of Medicine. He cares primarily for patients with common variable immunodeficiency and is drawn to the continuous challenges that immunology poses, because it is a constantly changing science.

Both gifted healthcare practitioners, Doctors Orange and Riedl also share a keen commitment to their patients. Dr. Orange is active in advocating for appropriate understanding and justification for immunoglobulin therapy, and Dr. Riedl thrives on being able to make a difference in the quality of his patients' lives, advocating for their care and volunteering at patient community events: "I love the

interaction with patients and I love the problem-solving aspect of what I do."

Perhaps what most makes the two physicians such valuable additions to our committee is that they both took the time to challenge us on content in IG Living, concerned that our readers receive the most accurate information. This is the stuff that makes an editor happy.

Welcome aboard!

The STRIDE Survey Is Still Available

Those of you with primary immune deficiencies can help improve immune defect diagnosis by taking the STRIDE survey (Study Targeting Recognition of Immune Deficiency and Evaluation). The survey is being conducted by immunologist Charlotte Cunningham-Rundles, MD, PhD, and it will help identify what medical problems patients commonly experience and what events led to their correct diagnoses.

"We need as many patients as we can possibly reach to take the survey," Cunningham-Rundles explained. "Their input is a very important part of our research, which will ultimately help improve evaluation and diagnosis of immune deficiencies."

You can find a link to the STRIDE survey at www.igliving.com.

We Won, We Won!

We are delighted to announce that IG Living has received a 2006 National Health Information Bronze Award. We were selected from nearly 1,000 entries judged by a national panel of health information experts.

The award reminds us of how it is that we have managed to finish our first year of publication with this issue of the magazine: We've enjoyed a wonderful collaboration with patients, care providers, patient organizations, advertisers, and the writers within each of these groups who continue to help define IG Living. We are honored to be working with you and grateful for your willingness to share so much so generously.

Thank you—a whole lot of mamas must be proud! ■

Have anything you'd like to add? Send your letters to editor@igliving.com.

Kit-Bacon Gressitt, Editor

The Heali

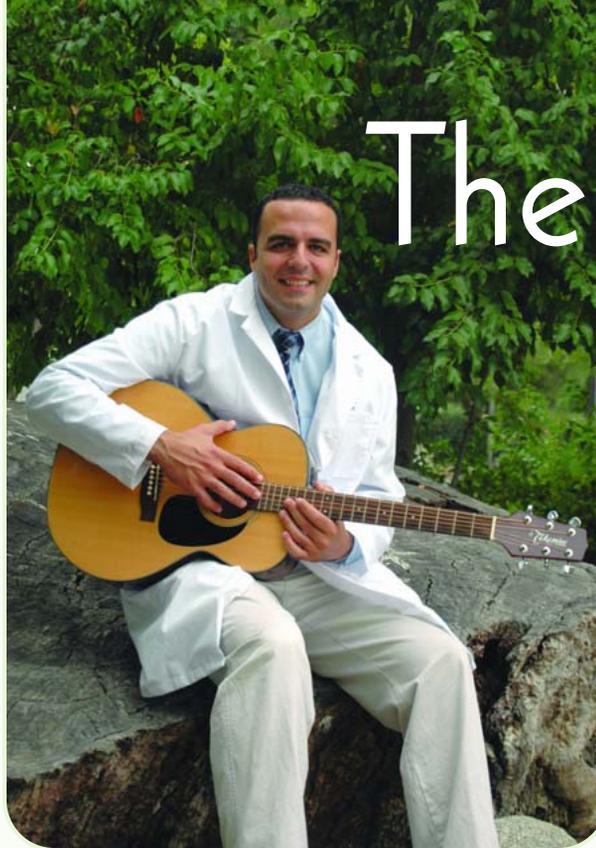
It's no secret that young doctors—interns, residents and fellows—are an overworked and tired bunch. But few have quite the claim to being tired that Dr. Raffi Tachdjian has.

While completing his medical training, Dr. Raffi, as he prefers to be called, founded a nonprofit organization, The Children's Music Fund; wrote and produced an album of his own musical works; and recruited artists and produced two additional CDs—to benefit the chronically ill children he has encountered and treated during his training. Yet, Dr. Raffi says he's not tired: "I'm energized by all that I've been able to do, I think I'm the lucky one—who gets to make a difference." In fact, when he's on call he can often be found sitting with his patients playing his guitar for them.

For the last two years, during his fellowship in allergy and immunology at University of California Los Angeles Mattel Children's Hospital, he has also been working on a new CD called "Open Your Window," the profits from which will support the Children's Music Fund, created while he was an intern at Boston's Mass General Hospital.

How Does He Do It All?

"My day starts at 7 a.m. and usually doesn't end until 2 a.m.," Dr. Raffi explains. "I work on the album usually five days a week, in addition to working clinic and running call. It sounds like a lot, but I love it—the medicine, the music, the patients. I love it all."



Dr. Raffi with a well-loved guitar.

Actually, it's not surprising that Dr. Raffi would be so caring. He learned service as a way of life from his family. His father, Dr. Vertran Tachdjian, is a pediatrician who gave up his private practice and began treating migrant farmworkers and the homeless in California's Central Valley.

"Giving to others was just part of our family tradition," Dr. Raffi says. "Our father taught us the importance of using your gifts for the greater good."

As a child, Dr. Raffi realized he had a gift for music. In the eighth grade he taught himself to play the guitar and piano—perhaps despite an attempt at formal training: "I only lasted a few lessons," he laughs. "I wanted to play music, not learn notes."

But Dr. Raffi did not start out intending to serve others through a music-oriented nonprofit organization. Rather, it was the inspiration of someone else that spurred him on.

Justin was a 15-year-old cancer

patient at Mass General when Dr. Raffi was a first-year resident. Their mutual love of music forged a friendship, and when Justin's long hospital stay began affecting his mood, the young resident convinced a local music shop to donate a guitar and lessons while Justin was in the hospital.

"Music was a language

that allowed Justin to open up. It was what allowed him to communicate with me. I realized there was something to it, and that more children could benefit." Sadly, Justin died at 16, but the idea he inspired lives on.

His experience with Justin motivated Dr. Raffi to create an album of his original music, and donate all the proceeds to buying instruments for chronically ill children experiencing long hospitalizations. "White walls, and stainless steel, that's what these kids see all day. It's easy to lose hope."

Dr. Raffi firmly believes that music is not only a window to the soul, but that it also has healing powers. Influenced by a 19th century Armenian priest, Komitas, who believed music's powers could heal, Dr. Raffi is beginning to study music's healing powers. "Now I need to prove the effects of music therapy through quantitative results," he explains. He hopes to research the effects of music therapy on patients with chronic pain and chronic illness.

ng Sound of Music

By Dayna Fladhammer

Music Is a Global Language

Through his work with chronically ill children, Dr. Raffi has come to believe that music is the true international language. It allows ill children, who typically sit passively in a hospital, to become active, even if it's only with their hands. "Music requires interaction," Dr. Raffi says, and for some kids, that's just what the doctor ordered.

When asked why he chose chronically ill children for his fund, Dr. Raffi seems to reflect for just a moment before answering. "They experience pain and suffering, potentially for life, dealing with a gloomy diagnosis that they can't shake. It's something that trails you forever. ...They need something to redirect to the positive. What better than music?"

The Children's Music Fund has now provided musical instruments to 45 patients. In collaboration, well-known Los Angeles music store West LA Music has agreed to provide the instruments at cost to the fund, allowing Dr. Raffi to provide more instruments to more children. Many of the CDs' fans are the doctors, nurses and family members of his patients. "The nurses are particularly kind with their support," explains Dr. Raffi.

Dr. Raffi encourages other doctors to identify patients who might benefit from musical instruments—

and he encourages them to present the instruments to the patients themselves. "I want them to experience the joy of giving the gift of music to a patient," he explains. "It builds the relationship when the child's doctor is the one providing the hope to them."



Open Your Window

Dr. Raffi spent months arranging the flow of his newest CD, "Open Your Window," a mix of different music styles. The final product was released in November, and is now available on The Children's Music Fund website: www.childrensmusicfund.org.

One of the most exciting aspects of this third CD is the addition of some famous artists who volunteered their time. "Once you explain to them what the fund is about, almost everyone says yes and checks egos at the door."

Included in the latest CD are:

- Children's musician and author Raffi (no relation to Dr. Raffi)
- Cellist Peter Ludwig, whose music focuses on tranquility and healing
- Mia Doi Todd, an artist whose work has been chosen for NPR's Best CDs You Have Not Heard List

The Children's Music Fund, now based out of Los Angeles, has received help from many sources.

The Board of Directors includes

- Peter Gordon, Berklee College of Music in Los Angeles
- Actor Tom Everett Scott of "ER" and "Saved"
- Visual artist and voiceover artist Vahe Berberian
- Carrie Becks of Red Marketing
- Corey Weiss of Palisades MediaGroup
- Dr. Lonnie K. Zeltzer, Pediatric Pain Program at UCLA

With growing support for the fund, Dr. Raffi is hopeful for its future. "I'd like the Children's Music Fund to continue to make a difference. I'd love to see it be a national program. In every hospital, children with chronic illness should have access to music. No matter what their diagnosis, they deserve the hope music can provide." ■

Visit the Children's Music Fund at www.childrensmusicfund.org.

Influenza Vaccination Rates

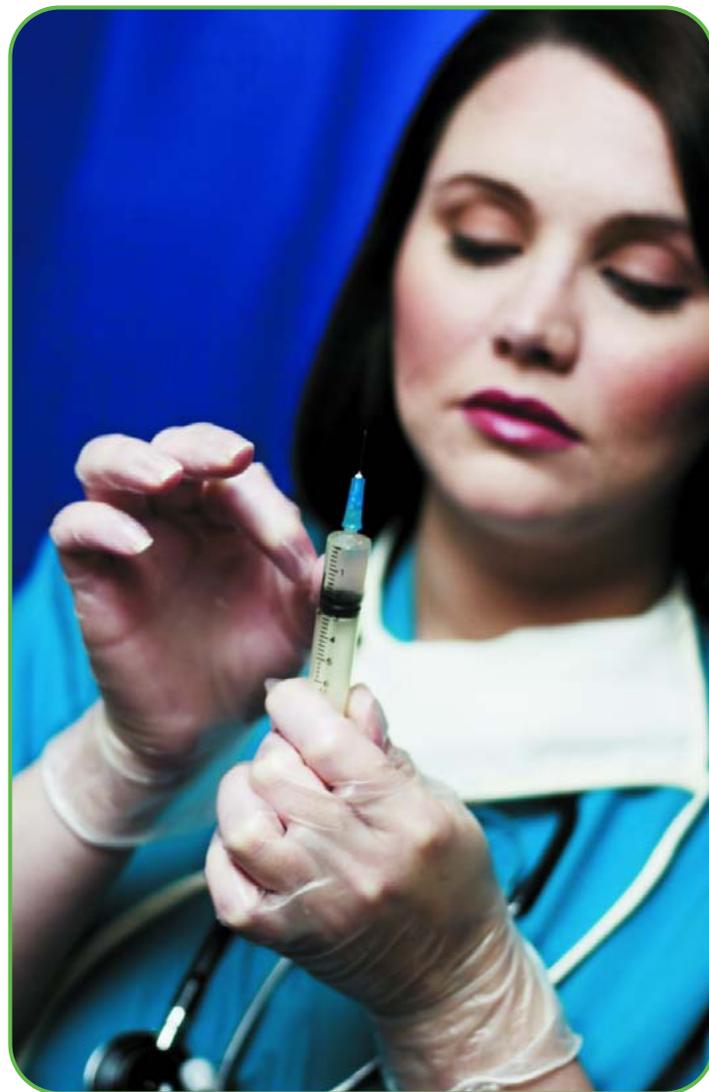
From the Centers for Disease Control and Prevention

With all the news coverage in the last few years of people scrambling to find a flu shot, it is interesting to note that not everyone recommended for annual vaccination and able to access it chooses to do so. Surprisingly, one such group that avoids flu shots is the people administering the vaccines themselves! In fact, only 40 percent of all healthcare workers were vaccinated in 2003.¹

Healthcare professionals—and nurses in particular—are key to preventing the spread of influenza, a debilitating and highly contagious respiratory infection. It is caused by a virus and leads to an average of approximately 200,000 hospitalizations and 36,000 deaths in the U.S. each year.² Because of their frequent and direct patient contact, nurses can spread the virus to patients in their care.³ This is problematic for the many patients at high risk for influenza-related complications that could lead to hospitalizations and even death. Influenza can also be spread from one healthcare worker to another or from patient to healthcare worker. In an era of nursing shortages, understaffing and mandatory overtime, nurses do not want to burden their co-workers by taking sick days related to something as easily preventable as influenza.

The influenza vaccine remains the best way for nurses to protect themselves, their families and the patients in their care during the annual influenza epidemic. An annual intramuscular vaccination, the influenza vaccine is one of few immunizations that are recommended for all healthcare professionals, regardless of any special conditions such as pregnancy, HIV infection, severe immunosuppression, renal failure, asplenia, diabetes, and alcoholism/alcoholic cirrhosis.⁴ Another option for most healthcare providers is the live intranasal influenza vaccine. This live vaccine is approved for use by healthy persons 5 to 49 years of age who are not pregnant and do not provide care for severely immune-compromised people who require care in a protected environment.

Since 1984, the Centers for Disease Control and Prevention (CDC) and the Advisory Committee on Immunization Practices have recommended that healthcare professionals (inclusive of doctors, nurses and other staff who work directly with patients) receive an annual influenza vaccination.



Because the vaccine is altered nearly every year to match the circulating strain and because immunity from the vaccine wanes over time, the vaccine must be given each year—ideally in October or November.

Vaccine Myths Abound

Despite the established benefits of the influenza vaccine, however, several misconceptions exist in the nursing community. The most common myth is that the influenza vaccine can actually cause influenza. In reality, the vaccine cannot cause influenza. Some nurses also mistakenly believe that they are automatically immune to influenza or have stronger immune systems merely because they work

for Nurses Need a Boost

around sick people every day. Because influenza viruses are constantly changing, past exposure to influenza will not provide protection against newly emerged strains.

Yet another misconception is that the side effects of the vaccine are worse than getting influenza itself. The truth is that the most serious side effect is an allergic reaction in people who have a severe allergy to eggs (the vaccine viruses are grown in eggs). For this reason, influenza vaccination is contraindicated for persons with an egg allergy. The most common side effects are redness at the injection site and a sore arm. These symptoms are mild and resolve in one to two days.

Finally, some people might argue that because the influenza vaccine is not 100 percent effective (it is 70-90 percent effective in healthy adults), they will get influenza anyway. However, even if the vaccine does not prevent all individuals from getting influenza, they are still likely to be far less sick than they would have been without the shot. The vaccine also greatly reduces the chance of hospitalization and death. People at greatest risk for influenza-related complications include: people 65 years and older; residents of nursing homes and other chronic care facilities; people with chronic pulmonary or cardiovascular conditions; people with diabetes mellitus; and children less than 2 years of age.

Nurses have long played a key role in preventing much influenza-related morbidity and mortality by ensuring that at-risk patients, particularly elderly patients and young children, are vaccinated against influenza every year. The time is long overdue for nurses to take care of themselves as well, and protect against the influenza virus by getting a vaccination. ■

1 CDC. *Prevention and control of influenza: Recommendations of the Advisory Committee on Immunization Practice (ACIP)*. *MMWR*. 2004;53(RR06):1-40.

2 Centers for Disease Control and Prevention, "Influenza: The Disease" November 15, 2004 (<http://www.cdc.gov/flu/about/disease.htm>)

3 National Foundation for Infectious Diseases, "Improving Influenza Vaccination Rates in Health Care Workers. Strategies to Increase Protection for Workers and Patients." 2004

4 CDC, *MMWR*. 2004;52(RR06):1-40.

Influenza 101

Although influenza is primarily spread by droplet transmission, the virus can also live on objects such as doorknobs, telephone receivers, utensils and food trays, beds and medical equipment for possibly up to one day. Some people infected with influenza may not develop symptoms at all, but may be infectious to others. For infected people who do develop symptoms, they can be contagious the day before they get symptoms. So nurses can transmit the virus even before they realize they are infected. The period of greatest contagion is during the first three days of illness, and can last for five to seven days in otherwise healthy adults.

Influenza usually starts suddenly and may include the following symptoms:

- Fever (usually high)
- Headache
- Tiredness (can be extreme)
- Cough
- Sore throat
- Runny or stuffy nose
- Body aches
- Diarrhea and vomiting also can occur infrequently but are more common in children

General treatment for influenza includes bed rest, drinking plenty of fluids and taking over-the-counter medicines such as acetaminophen. Children suspected of having influenza should not be given aspirin as this may increase the risk of a complication known as Reye syndrome. In addition, there are several prescription antiviral medicines that can help prevent influenza infection and, when used within the first 48 hours of illness, can reduce duration and severity of the influenza illness. Some people infected with influenza may also need antibiotics if their healthcare provider suspects a secondary or concomitant bacterial infection.

For more information about influenza and the influenza vaccine, visit www.cdc.gov/flu or call 800-CDC-INFO (800-232-4636).

Readers Write



Flu Shots and Immune Deficiencies

I wish to clarify a statement attributed to me in the August-September 2006 IG Living article "Is Flu Vaccination for You?" I was quoted as saying "There's less of a chance that it's [flu vaccination] going to work for someone with autoimmune problems." IG Living corrected this statement in the last issue to indicate that flu vaccination is less likely to be effective in individuals with *immunodeficiency* problems, not autoimmune problems.

There is clear research evidence that immunodeficient patients often fail to produce protective antibodies to immunization. I am unaware of any similar data for patients with autoimmunity. Therefore, the readership of IG Living should understand that immunization is presumed effective for individuals with autoimmunity. It should be emphasized that preventative immunizations, including flu vaccines, are an important component of individual and public health programs.

Sincerely,
Marc Riedl, M.D., M.S.
Assistant Professor of Medicine
Clinical Immunology and Allergy
UCLA—David Geffen School of Medicine

Mercury-induced Myasthenia Gravis and IVIG

In early March of 2003, I was sitting in the laboratory at work, talking with two plant mechanics, when for some reason my speech started slurring. I attributed it to being tired from working extra hours. After waiting a few days with no improvement, I contacted our family doctor for an appointment. I went through testing for everything from a stroke to diabetes. There did not appear to be a cause. My symptoms progressed to having trouble swallowing and gripping objects and general fatigue.

As an environmental engineer with some training in toxicology, I started researching my symptoms and comparing them with the toxicity of the hazardous materials I worked with. My symptoms were common to mercury poisoning and myasthenia gravis (MG). Apparently I had reached a chronic level of mercury poisoning that triggered the MG and caused damage to my nervous system.

Mercury-induced myasthenia gravis was confirmed in the United States and by the World Health Organization in 2005. Myasthenia gravis is an autoimmune disease that gradually causes muscles to lose their strength and function: The body produces antibodies that attack a person's own tissue. Mercury is one of the more recently confirmed trigger mechanisms of MG.

A review of my lab work and medical histories showed that I had acute mercury poisoning in 1999 that reached a chronic level in 2003. In January 2005, my AChR blood test for myasthenia gravis was positive. However, there is a conflict between the treatment for mercury poisoning and the drug treatment for MG: The drugs normally given for MG make the neurological symptoms of mercury poisoning worse.

I was unable to receive the preferred drug treatment for MG and my health continued to decline. Then I visited a new neurologist who started me on IVIG treatment and the results were impressive. Almost immediately the improvement was noticeable by my family. I now receive monthly doses of IVIG. I have no side effects from the therapy, and the symptoms return slowly, unless I overdo physical activity.

I have started league bowling with my son and daughter-in-law once a week, and I am attending night classes at the community school.

My wife, Maribeth, has assumed most of the yard work and I have taken on the inside domestic work and cooking. The swap of household duties has worked out well—we both enjoy the change. I am able to play my guitars again, and am optimistic that by being removed from the hazardous environment I have a good chance of being one of the few who have had a spontaneous remission of MG.

Because more environmentally unsafe chemicals are being dumped in the air we breathe and water we drink, I would suggest that physicians become more familiar with these causes of diseases. Environmental hazard exposure reactions can mimic diseases, and for me, IVIG was an excellent first order of treatment.

—Arthur Slack, Florida

The Best Laid Plans

By Dayna Fladhammer

I didn't plan our life this way.

When I used to imagine a life with a family, it included trips to amusement parks, weekends camping, the occasional scraped knee, yearly checkups with the pediatrician.

The life I imagined never included children with a chronic illness. It certainly never included trips with three kids to an infusion center to get hooked up to IVs. Without a doubt, it never included the amount of planning and calculated risk that goes into every day of our lives.

Looking back at our lives over the past five years, I feel at peace with where we are now, but that was not always the case. There was a time when I was angry with this disease, and all that it required of us. I wanted to control what felt so wildly out of my control. When my kids were first diagnosed, I didn't just want to know what they had, I wanted to know how they got it, when they would out-grow it, and what they would encounter in between. I was angry and depressed, and I was in survival mode. I took my kids almost nowhere, because every time we went somewhere, someone got sick.

We were still in crisis mode, trying to tame the beastly infections that seemed to attack so frequently, when all three of my kids started on intravenous immune globulin (IVIG). Then life settled down, we started to get healthy, and I spent months grieving. Of course, my children were alive and finally healthier, so what I was grieving, I initially didn't know. Eventually, though, I realized I was grieving the loss of the life I had planned for our family.

When I had originally imagined Charlie beginning school, I saw a smiling Charlie bouncing off to his first day of kindergarten, silent tears running down my face as I sent him out to brave the world.

In reality, Charlie's entrance to kindergarten entailed

much more than that: It included preplanning; assurances he could drink from a water bottle, not the germey fountain; going over procedures should he get a cut, making sure every adult who might encounter him would know what to do; going over his relevant health history; and getting an individual education program in place.

Kindergarten has been a struggle to let go and pray that Charlie has learned the lessons we've taught him about his health: don't share a drink with anyone, wash your hands, and move away from someone who is coughing or looks sick. It's been a leap of faith that others can care for him and understand enough about his disease to protect him when he can't or won't protect himself.

However, when I start to get down that school—and our life—takes more effort than I had originally dreamed, I remind myself that Charlie can even go to kindergarten! This is something he would not have been able to do pre-IVIG. Our life may take more time and effort, but we've encountered families whose children are terminally ill, and that keeps our struggle in perspective.

So, all the planning and preparing and taking care, this is our normal. Dealing with the disease and its chronic nature has forced me to let go of what I thought our life would be like, and instead, embrace what it is.

I know we will encounter new milestones and I will again grieve for what I had wished for my children. I suspect this will happen for the rest of our lives. But now as I grieve, I know something I didn't the first time: I know what I'm grieving for, and I know we'll get through it, together, and come out stronger. Of course, I would take this struggle away from our family in a heartbeat if I could, but since that's not possible, we'll continue to live our lives, grateful that IVIG allows us the freedom to really live it. ■



Learning to Speak Medicalese

By Lauren Gerstmann, MPH

Lupus. Multiple sclerosis. Primary immune deficiency. On the surface, these diseases may not seem to have much in common. But they are all systemic disorders that impact the health, well-being and lifestyle of the patient and the entire caregiving network. Any chronic, system-wide disorder necessitates care not only by a primary physician, but also by an entire network of specialists. While the disease itself can be debilitating, finding the right doctors and hospitals, and navigating the costs, can be almost as overwhelming. It is almost as though caregivers need to learn a new language: “medicalese.”

Choose a Doctor Who'll Speak With You

The first step is finding the right primary care physician, someone who will get to know the entire patient and have some familiarity with the constellation of symptoms. While it is helpful to have knowledgeable primary physicians, it is almost more important *who* they know rather than *what* they know. Their primary function will be to help you coordinate care and put each specialist's input into context. To that end, primary physicians should feel comfortable referring you to, and consulting with, other physicians. Just as critical, they should be comfortable consulting with you. As the patient or caregiver, no one knows the situation better than you do!

Joan's 1 toddler, Jimmy, had been on inhaled asthma medications for several weeks, and his pediatrician decided to taper the dose. One week later, the pediatrician listened to Jimmy's chest, and it sounded clear. But Joan mentioned

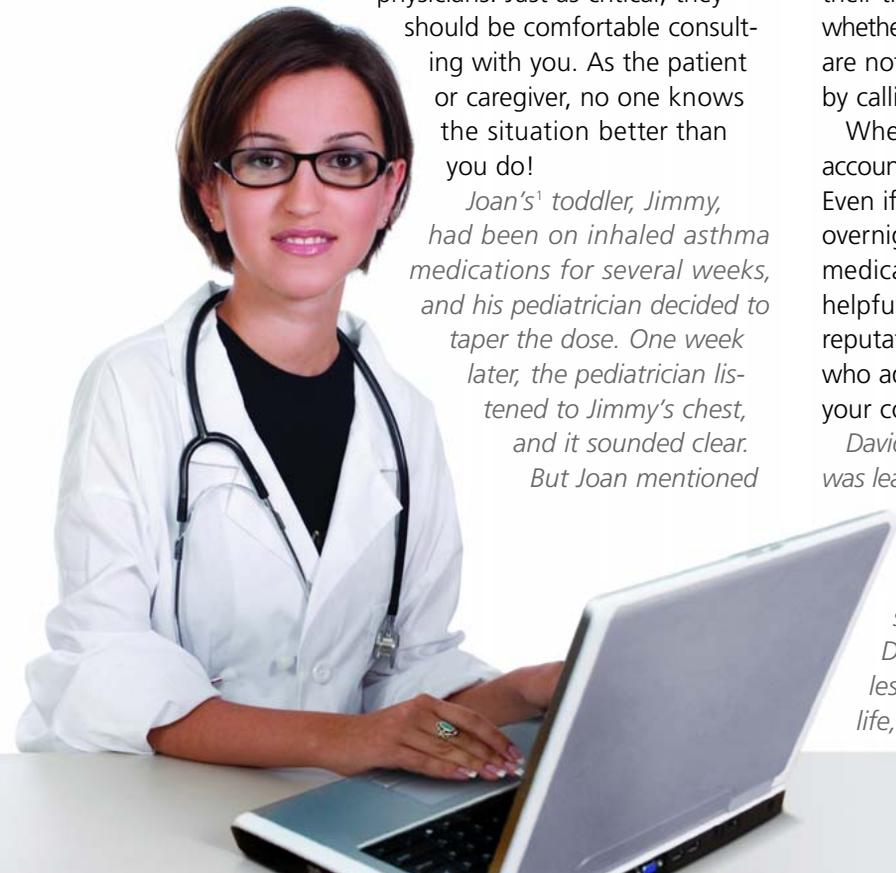
that since the medication had been cut, Jimmy had been sleeping poorly. Based on the information she provided, the pediatrician increased his medications, and Jimmy began sleeping again.

It is important that you choose a primary physician who is accessible. Different people, however, define accessibility differently. It may mean the physician is physically close to your home or office or has easy parking, or it may mean he or she has Saturday office hours or willingness to communicate with you via email.

Your relationship with the various specialists you consult may be quite different, and may be much less personal. So, it becomes critical that you have a quick and objective way to assess their skills. One simple suggestion is to consult the online databases of medical specialty societies, such as the American Academy of Allergy, Asthma and Immunology or the American Society of Clinical Oncologists. This will let you know what American Board of Medical Specialties Certifications they have completed. If your doctors are American Medical Association (AMA) members, the AMA website will also tell you their phone numbers, exact locations and office hours, where they received their training, to what hospitals they admit patients, and whether they accept Medicaid or Medicare. If your physicians are not AMA members, you can ask for this information by calling their offices.

When you choose doctors, it is critical to take into account the hospital(s) into which they admit their patients. Even if you are not anticipating a major procedure or an overnight stay, the hospital will be a critical part of your medical regimen. Word-of-mouth can be surprisingly helpful here. If one of your hospital options has a bad reputation, don't go there! If you want to see a physician who admits only to that hospital, be frank with him about your concerns.

David had a great relationship with Dr. Jang, but Dr. Jang was leaving her practice. David planned to continue seeing her at her new practice until he learned she would admit patients only to a local community hospital, not the research institute with which she had previously been affiliated. David called Dr. Jang and discovered she was switching to the less-demanding practice to accommodate her family life, not because she thought it was medically superior.



She suggested David choose a new physician who would be able to admit to a hospital that better served his needs.

In addition to word-of-mouth, there are objective indicators of a hospital's performance. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is an independent, nonprofit organization governed by a 29-member Board of Commissioners that includes nurses, physicians, consumers, medical directors, administrators, providers, employers, a labor representative, health plan leaders, quality experts, ethicists, a health insurance administrator and educators. JCAHO gives out a Gold Seal of Approval™ to organizations that perform satisfactorily on performance review. To keep their Gold Seal, an organization must pass muster every three years (every two years for laboratories). JCAHO standards assess performance in key functional areas, such as patient rights, patient treatment and infection control. You can find very comprehensive information about their standards, and a searchable database of accredited institutions, at <http://www.jointcommission.org>.

Often, a hospital website can be a great source of information, although it might not be objective. Many of the larger hospitals profile their physicians and programs online. So, for example, you can see if the hospital has a single rheumatology specialist or a comprehensive team.

Although you should do all you can to make informed choices about your physicians and hospital, these choices are often mediated by financial considerations and distance. Some tips follow to maximize the efficacy of your treatment when your choices are limited.

Taking Medicaese on the Road

If you do not live near qualified providers, and your health and finances permit, you can travel to medical specialists who can help you. You or your primary care physician should do extensive research before making this decision, in order to make sure you have identified the most appropriate place to go. People with chronic conditions will often form online communities (LISTSERVs), which can be a great source of support and information. If you are a LISERV member, ask your peers for recommendations. Call disease-specific organizations (e.g., the ALS Foundation, The Myositis Association or the Immune Deficiency Foundation) to see if they have any recommendations. Review the medical literature online or at your local library to see if there is anyone conducting research in your area. Once you have identified the doctor you want to see, call him or her to talk about your case. You can gauge a lot about a doctor's expertise and bedside manner over the phone.

Although it may be easy to make the decision to travel, the practicalities can be overwhelming.

Carol and Jake's daughter, Rachel, was in terrible gastrointestinal distress and was showing the preliminary signs of an immune deficiency. The family lived in the rural South and had very limited access to gastroenterologists, immunologists or any of the other specialists their daughter needed.

"We knew our daughter was in crisis ... but [the pediatrician] decided that she wanted to watch and wait." Carol knew that her daughter was immunocompromised and felt that she would "crash" and end up in an intensive care unit if she wasn't treated immediately by someone more knowledgeable and more aggressive. Although this was a complicated decision, they decided to take a commercial flight, while taking many measures to protect their daughter. First, Carol wrote a letter to the airline outlining the measures that the airline would need to take to protect Rachel. She had Rachel's doctors sign the letter, and she kept it with her throughout the trip. They took a nonstop flight, boarded the plane last, asked for bulkhead seats, and made sure that they stayed only in low traffic areas of the airport. Before going to the airport, Rachel had an intravenous immune globulin treatment to boost her immunity to its maximum level.

Carol and Jake also took measures to make the trip a positive experience for Rachel, who had not had many opportunities for a family vacation. While they weren't able to see any sights, they spent special family time together and budgeted a little extra for toys and arts and crafts.

As a side note, there are several companies that charter private flights for medical treatment.²

Much has been written about the lack of available specialists in rural areas. For every 10,000 people in rural America, there are 5.3 primary care providers and 5.4 specialists, while there are 7.3 primary care providers and 13.4 specialists for every 10,000 people in urban environments.³ If you are not near the specialists you need, and if you are unable to travel regularly, technology can allow you or your primary care physician to coordinate with distant specialists (e.g., through email, home health virtual visits, and electronic radiology consultations). A very good summary of the available technological options can be found at: <http://www.chcf.org/documents/hospitals/RuralHealthCareDelivery.pdf>.

Insurance as a Second Language

Just as it is important to make choices about your physicians, hospitals and travel options, it is also critical to know about your options for medical insurance.



Seek and Ye Shall Find

It is important to supplement the information that your physicians give you with your own research. Try the following information sources:

WebMD (www.webmd.com) and eMedicine (www.emedicine.com) are valuable resources. They provide good general information and are a great starting point.

The National Organization of Rare Diseases (NORD, <http://www.rarediseases.org/>) is also a great starting point. In addition, NORD maintains a comprehensive list of patient organizations, foundations and registries that help individuals and families affected by rare diseases.

Insurance policies fall into three categories: HMO, POS and PPO. An HMO (health maintenance organization) is the least expensive option, but requires that you use only member physicians. One overlooked advantage of an HMO may be that they can provide members with a comprehensive medical record. For example, Kaiser Permanente physicians keep all of their dictated consultations, procedure notes and laboratory results in a computerized database. This minimizes the necessity of recordkeeping by their patients. In theory, if you need medical care that is not available within the system, most HMOs will support you. Anecdotal evidence, however, suggests that this requires negotiating a lengthy and difficult system of appeals, and it is not guaranteed to succeed.

A POS (point of service) functions like an HMO, but allows patients to choose "out of network" providers for a higher co-pay or deductible.

A PPO (preferred provider organization) offers partial coverage over a loose network of doctors and hospitals. You can also choose "out of network" providers for a higher co-pay or deductible. This is by far the least cohesive situation, and it is also the most expensive, but it offers access to the widest range of providers and is by far the most flexible.

While most people are privately insured, the United States government provides health insurance through the Medicare program to people age 65 or older, people under age 65 with certain disabilities, and people of all ages with end-stage renal disease (permanent kidney failure requiring dialysis or a kidney transplant). (See <http://www.cms.hhs.gov/MedicareGenInfo/> for more information.) Another government program,

Medicaid, targets low-income individuals and families, and coverage policies vary from state to state. (See <http://www.cms.hhs.gov/MedicaidGenInfo/> for more information.)

The Georgetown University Health Policy Institute has written "A Consumer Guide for Getting and Keeping Health Insurance" for each state and for the District of Columbia. Guides are available at <http://www.healthinsuranceinfo.net/>.

Writing the Book on Medicaese

If you are consulting with multiple physicians, keep a comprehensive record of all visits and outcomes. Make a list of all your current physicians (with contact information), medications (with dosage), allergies and diagnoses (including the date of each diagnosis). Keep a table of all illnesses and doctor visits that contains information on symptoms, diagnoses, lab work (with results) and procedures (with results).

When you meet with a new physician, give him or her a copy of the record for your file. At first, the doctor may take only a glance, but when you refer to it to answer questions, he or she will begin to take it more seriously.

"Medicaese" is a lot to learn, but there are many resources out there to help you become proficient. The more active a role you take in your or your loved one's care, the better care you will receive. As Ralph Waldo Emerson wrote, "Knowledge, Virtue, Power are the victories of man over his necessities, his march to the dominion of the world." ■

1 All the situations presented in this article are factual; however, names have been changed to protect privacy.

2 Here are a few options; please bear in mind that these services may change their availability, eligibility requirements, and insurance options at any time:

National patient travel center: (can help match patients with appropriate transportation) <http://www.patienttravel.org/AFAS/nptc.htm> 800-296-1217

The Corporate Angel Network (specifically for cancer patients) <http://www.corpangelnetwork.org/about/index.html> 866-328-1313

Air Compassion (bed to bed ambulance service): <http://www.aircompassionamerica.org/> 866-270-9198

Miracle flights (free flights for children) <http://www.miracleflights.com/> 800-359-1711

Mercy Med-Flights: 800-781-2959; 828-387-3794;
Email: Inquiries@AirCharterLeasing.com

Mercy Medical airlift (free flights for people with financial need) <http://www.mercymedical.org/>

3 Reschovsky, JD and Staiti, AB, "Access and Quality: Does Rural America Lag Behind?" in Health Affairs, Volume 24, Number 4, July/August 2005 p.1128-1139

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Is Your Infusion Clinic One of the Good Guys?

By Dan Bennett

It sounds like a plot for a bad science-fiction movie.

A healthcare provider infuses a patient with the wrong medical product. And even if that product is only saline solution, when the patient desperately requires immune globulin (IG) or some other vital drug, it's a bad scene indeed.

Denise Hasenstab is an Orange County, Calif., patient who recently sued an infusion clinic for altering or replacing her IG injections with saline solution—for seven years.

Expert testimony from outside medical experts indicated that Hasenstab's claims were accurate, that she indeed was not infused with the product she needed, and that her health suffered. The clinic denied medical negligence, but admitted faulty record keeping, and settled the case for \$300,000.

"Dealing with the emotional aspects of this experience is beyond words," Hasenstab said. "It is an absolutely devastating thing to find out that doctors you trusted, doctors who took an oath to help you, lied to you purposely. It's one thing when it's an innocent mistake, quite another when it is calculated."

Though Hasenstab settled the case, the state medical board in California continues to investigate the clinic. Meanwhile, Hasenstab now receives her infusions at the University of California Irvine Medical Center, and after six months of treatment, at last has begun feeling better.

"There is no dollar amount I ever could have received that could even come close to making up those lost years of my life," she said. "Money



can't bring back that time with my children. Those years are gone."

Now, Hasenstab says she will become an advocate for better monitoring of infusions and victims' rights, and she offers advice for patients just starting their infusions. Though Hasenstab says she recommends teaching-hospital settings such as the one she visits now, patients who visit infusion clinics can help protect themselves.

"To start with, research the doctor's credentials," she recommends. "Check to see if the doctor is board certified. If the doctor does not have hospital privileges, that's a red flag. Get as much information as possible about the drug product they expect to give you. You may feel run-down when you first start, so find an advocate such as a family member or friend who can ask questions on your behalf. Call the manufacturer yourself and

ask questions about the product. And make sure the product is clearly labeled. If not, there is a problem."

In other reported cases during the last several years, law enforcement authorities have investigated and sometimes prosecuted healthcare providers who are often motivated by the potential financial rewards of insurance fraud and other illegal activities.

Such things happen, if rarely, so what can be done? How can a patient in need of regular IG infusions trust that the proper product is used? What are the questions a patient can ask when visiting a clinic for the first time, and how can the patient monitor his or her own ongoing care?

Healthcare providers at infusion clinics echoed Hasenstab's advice for infusion patients.

"A patient should always know what brand they are using for their infusions," said Kristin Epland, a nurse practitioner at Midwest Immunology Clinic in Plymouth, Minn. "One of the first ways a patient can discern what infusion centers are giving is understanding what they are supposed to be giving. My opinion is that patients should not switch back and forth between products, because of supply issues and adverse reactions. An important step for patients is taking control of their own infusion needs."

At Midwest Immunology Clinic, patients are provided with diaries to keep track of their infusions. "Among other things, these diaries act as safety checks," Epland said. "So, if there's a product recall, even if the infusion nurse makes a mistake, the patient will have a record of what

product they have taken. Every time a patient is getting an infusion, they should ask an infusion nurse what the product is. It's crucial that patients maintain control of their therapy."

Epland says first-time visitors should ask the clinic personnel how many IG infusions they do in a week.

"If the answer is only one, then maybe they don't have as firm a standard policy on infusion procedure as a clinic that does 100 infusions a week," she said.

Epland often coordinates follow-up infusion treatments at other locations for patients who live a long distance from her clinic. She monitors the treatments performed on her patients at the other infusion clinics.

"Even smaller locations are now able to do complicated infusions, so again it's important for the patient to stay on top of the treatments, especially if the clinic is not experienced with a particular infusion," she said.

Communication with primary physicians is essential, infusion clinic specialists say. If the immunoglobulin levels are not correct following three months of treatments, start asking questions.

"People can lie to you, though my experience in this field is that the overwhelming majority of providers are honest, dedicated professionals," Epland said. "The stopgap is the patient. Never be afraid to ask questions."

Though the illegal substitution of medicines can fall under federal law statutes in some cases, infusion clinics are for the most part regulated by each state's department of health services, which approves licensing and investigates complaints.

The physicians at infusion clinics, meanwhile, are monitored by state medical boards, which maintain the power to suspend or revoke licenses to practice medicine. Departments

of health and state medical boards often work in tandem to investigate complaints. In some cases, clinics are shut down by state health services when law enforcement authorities begin making inquiries, at least temporarily, until the issue is resolved.

Most state medical boards and health services departments have websites where the public can research whether a physician or infusion clinic has come under previous investigation. These agencies also have dedicated phone numbers to handle patient complaints.

Because stand-alone infusion clinics can often serve as "one-stop shops" for a variety of medical services, monitoring these clinics can be a challenge. And the challenge starts at the source.

Ray Wilson, chief of the drug and consumer products division for the California Department of Health Services, says his department monitors for fraud starting with release of the drug from the manufacturer.

"What happens at an infusion clinic is one thing, but consumers should know that drugs are monitored from the time they leave the manufacturer," Wilson said. "If a drug is misrepresented by its label or in some other way, our department has the responsibility of taking action."

Some such instances can be accidental, some on purpose, but Wilson says the majority of manufacturers take careful steps for accuracy.

"As the costs of healthcare products continue to rise, counterfeiting and things like that could become even more of a problem," Wilson said. "But manufacturers know it's in their best interest to be careful and stay on track, for many different reasons, including their own liability."

For the patient, it all starts with questions and record keeping.

"One of the things patients can do is keep their own infusion logs," said

Kimberly Duff, a clinical nurse for IG provider NuFACTOR. "When we do an infusion, we peel the sticker off the bottle and place the sticker on the infusion sheet. The patient can then take the bottle and use it to record the infusion on a log they keep privately. This way, they know what the product they received was supposed to be, and when they received it. It's a good way of tracking."

Duff also encourages patients to become familiar with their own testing and lab work.

"The patient should monitor their levels," Duff said. "Know what your numbers are and what they mean. If you suspect those numbers are not what they should be, always check with your physician."

Trust becomes a big element.

"Identify one of the providers you have a comfort level with, and develop a relationship with somebody you trust at the clinic," Duff said. "With trust, you can help alleviate the fear of asking questions." ■

Editor's note: It is important to note there may be valid medical reasons why levels and labs don't predictably respond to proper doses. While it is important for patients to ask questions about their treatment, unusual levels are not necessarily an indicator that deception is taking place.

For More Site of Care Information

The American Academy of Allergy, Asthma & Immunology website, www.aaaai.org, has downloadable site-of-care guidelines, http://www.aaaai.org/members/resources/initiatives/ivig_toolkit/ivig_site_of_care.pdf.



IMMUNE DEFICIENCY FOUNDATION

Volunteer Support Network

By Jeff Siegel

A couple of times a month, Melaine Zeigler receives a phone call or an email from someone who has just been diagnosed with a primary immune deficiency disease (PIDD) or has questions about living with the disease. The questions are usually the same—What do I do? How do I cope? What is this thing?—and so are Zeigler’s answers.

“The most important thing to let them know is that they aren’t alone,” says Zeigler, a PIDD patient herself. “It really helps them to know that there is someone on the other end of the phone who has had a similar experience. And my journey, though it has only been eight years, has been so different from others that I can tell them, ‘If this doesn’t work, you have other options.’”

In this, Zeigler is not alone. She is one of many volunteers who are part of the Immune Deficiency Foundation (IDF) Peer Support Program. Each month, the IDF office in Baltimore matches volunteers such as Zeigler with patients or family members looking for support.

Whether a patient is newly diagnosed or has been living with a PIDD for years, a call to IDF can help connect patients and their families with others who have gone through similar situations. The volunteers share experiences, encouragement and understanding. The program’s goal is to help patients and family members become their own advocates.

“They’ve heard all of the medical jargon in the doctor’s office, but they haven’t been able to talk to someone who has been through the same thing,” says Katherine Antilla, the IDF’s director of education and volunteer development. “They need to know that they aren’t the only ones out there who go through this.”

And it couldn’t be easier for patients to participate. Just contact the IDF by phone or email. Typically, when a new patient calls or emails the IDF office, Antilla matches him or her with someone who lives in the same part of the country or has been through a similar experience. The IDF website also has information about their other services, including regional conferences and seminars, educational services and family outreach.

“If you have appendicitis or a gallbladder removed or a broken leg, there’s a common understanding about what’s involved,” says John Seymour, PhD, a member of the IDF board whose wife and youngest daughter have been diagnosed with PIDD. “But immune diseases are so unusual, there’s no common understanding, no support for what you’re going through. Everyone knows what a broken leg is and what it means, but so few people know what immune diseases are. They can’t understand what it is, which is why so many people feel they’re in it by themselves.”

Seymour, who teaches family counseling at Minnesota State in Mankato, Minn., frequently speaks at the regional conferences, while his wife and daughter attend, along with his older daughter, who doesn’t have a PIDD. The conferences are family affairs with relevant sessions for all ages and situations.

Says Seymour: “It’s an opportunity for all of us, me as a spouse and dad, for my wife and daughters, to talk to other people who are our age and have our experience.”

The peer support program is also an opportunity for patients who have made substantial inroads against their disease, often with the help of other volunteers, to support their community. “It’s part of the challenge in life to give something back,” says Seymour.

Or, as Zeigler describes it: “The IDF is the most positive influence in my life.” Since her diagnosis in 1998 when she was pregnant with her second child, she has led a full and interesting life—and even teaches yoga and fitness classes at her local YMCA. “When the IDF started its program in Minnesota, I signed up. I said, ‘I’m new, what can I do to help?’ This has been an educational journey not just for myself, but for others.”

And an effective journey as well. ■

To find a peer contact in your area, phone the IDF at 800-296-4433 or email idf@primaryimmune.org. IDF will match you with a volunteer with whom you share a similar diagnosis or circumstance.

Visit the IDF website at www.primaryimmune.org.

Meet Megan



Loney

Megan Loney leads a seemingly typical life for an ambitious 27-year-old. She owns a condominium in downtown Seattle, works a full-time job in insurance claims adjustment, and enjoys traveling and hanging out with friends and family in her spare time. She is a twin, an athlete and a true philanthropist, with a lifelong dream of becoming a police officer.

There is one thing about Megan's life, however, that is not so typical. Last December, her world drastically changed when, after five years of misdiagnosed illness, she learned that she has common variable immune deficiency (CVID). While the journey to her diagnosis was challenging and often frustrating, having a real answer at last was a relief for Megan—and a disappointment.

"I was happy that we finally knew what was wrong with me, but at the same time I was disappointed that I would have to infuse every day," said Megan. "At first, it was a big change in my life; it was hard. You never think you will have to give yourself shots."

Realizing what a difference an infusion can make on her daily life, though, Megan has begun to embrace her ongoing adjustment to living with CVID. "Within a few hours of infusing, I feel much better, my energy is up." And, although you may think infusing would make it difficult to continue with some of the activities Megan has always enjoyed, she is learning how to make her treatments part of her daily routine; she has been able to continue traveling and enjoying life.

In fact, Megan recalled her first time camping after her diagnosis and having to infuse in the front seat of the truck one evening:

"As I was sitting there with all of my supplies, just about to insert the needle, I couldn't help but wonder what a policeman would think if he walked by and saw me inside a truck, in the dark, poking myself with a needle—it was a funny moment."

With a good sense of humor in her tool kit, Megan has also learned that she is not alone as she treks up the learning curve of living with an immune deficiency. Her family, friends and boyfriend have been eager to learn with her. "They have all been really supportive. My boyfriend has been amazing and has had a great attitude about it—he's not afraid of the disease—he understands the administration process and asks a lot of questions.

"It's often hard to stay optimistic on my own," Megan continued, "but it helps to have such a strong support system. I find that talking about it has really helped me deal with it—they are all interested in learning more about it, which makes it even easier."

Megan looks forward to being a part of her new-found community and, although she is unable to pursue a career in law enforcement due to recurring illness, she feels that joining the IG community will be equally satisfying because she will be helping others who have recently been diagnosed with CVID. "In a way, I feel blessed to have been diagnosed at this age, because I am more mature and able to better deal with it. I understand that I am in control of how I feel."

With her determination to make a difference as strong as ever, Megan's lifelong dream of helping others lives on. ■

By Alma Lucy Morales

On Becoming a Patient Advocate: Our Voices Really Do Matter!

By Melissa Schweitzer



When I left my job as a genetic counselor for a job as a patient advocate with the Immune Deficiency Foundation (IDF), I found my counseling skills transferred well to the one-on-one interactions I had with the thousands of families I talked with at IDF. And, I understood the community's issues, having common variable immune deficiency (CVID) myself.

However, had anyone told me then that my patient advocate job would evolve into my next position, which includes providing testimony at congressional hearings, I would have thought he or she was crazy. The prospect of speaking in front of government officials is intimidating, but that's what I'm doing!

So, you might ask, how have I handled it, why do I do it, and how can you do the same?

The answers are: You must know your message, have a passion for it, and practice. And the current IVIG reimbursement crisis has sparked my passion, allowing me to speak loud and clear on behalf of all patients who rely on this therapy.

On August 30, I spoke before the Department of Health and Human Services Advisory Committee on Blood Safety and Availability (ACBSA). My purpose was to inform the committee about a meeting held on August 28 to discuss the formation of the IVIG Access Coalition. The first of its kind, the meeting brought together patient communities for whom IVIG is a lifesaving therapy, healthcare providers who treat these patients, and staffers from key congressional committees. The participants shared the common goal of restoring access to IVIG for patients who have problems due to inadequate reimbursement from Medicare and private payers, unavailability of product, and lack of access to sites of care.

I explained to the committee how vital IVIG therapy is to my own well-being. Because of IVIG, I enjoy a successful career. Because of IVIG, I am a wife to a wonderful husband and a mother to two beautiful children. And, because of

IVIG, it is my mission to work toward a solution that restores IVIG access to my fellow patients.

If I had to be born with a chronic disease, at least it's one for which there's an effective therapy. Many of my fellow patients may have

thought the same when they were diagnosed and prescribed IVIG. It is unlikely they envisioned the horrible day when they would be told their IVIG was not available or that they could no longer receive it in their physician's office because the doctor could not afford to treat them.

The last time I spoke before ACBSA, in May 2005, I had the opportunity to meet another patient, Pam, who shared her story of IVIG access problems.

I vividly remember Pam. She had chronic inflammatory demyelinating polyneuropathy (CIDP) and myositis and was unable to get her IVIG on a regular basis. I remember her tears as she begged the committee to help find a solution to the IVIG access problems. I remember the tears we shared together when we met after testifying. I remember the tears I shed when I learned of her death this past spring.

The creation of the IVIG Access Coalition is an effective step toward restoring access to IVIG for all patients who rely on it. While the various patient organizations represent different constituencies, they share the common goal of saving the lives of patients in need. We can best accomplish this goal by coming together to speak with one voice—loud and clear—for the entire community of patients. We should not have to lose another patient or watch patients' health decline because of a lack of access to IVIG!

As patients with chronic illnesses, we deal with the fragility of our health and its impacts daily, which can help us develop the strength that often comes from adversity. This strength gives me the courage to let my voice be heard, to help myself and other patients. I hope you'll join me. ■

Melissa Schweitzer is an associate at Washington Strategic Consulting.

The Night Before IVIG

By Mark Haggard

'Twas the night before IVIG
And all through my kid
Many creatures were stirring
Because he has PIDD

My son was all nestled
Snug in his bed
While colonies of pneumococcus
Infected his head

And I in my T-shirt
With Ma settled in tight
Had just prayed to God
That he'd sleep through the night

Then from the upstairs
There arose such a clatter
We jumped from our bed
To see what was the matter
To the upstairs
I flew like a bird

Toward the sneezing and coughing
And wheezing I heard

I asked "Are you OK?"
Upon first inspection
And I knew right away
It was sinus infection

He was covered in sweat
From his head to his belly
And out from his nose
Came gobs of green jelly

With a deep sigh
My wife looked at me
"It'll be over tomorrow
He has IVIG

"No shingles, no otitis,
No pox or bronchitis
No pneumonia, sinusitis,
No herpes or meningitis

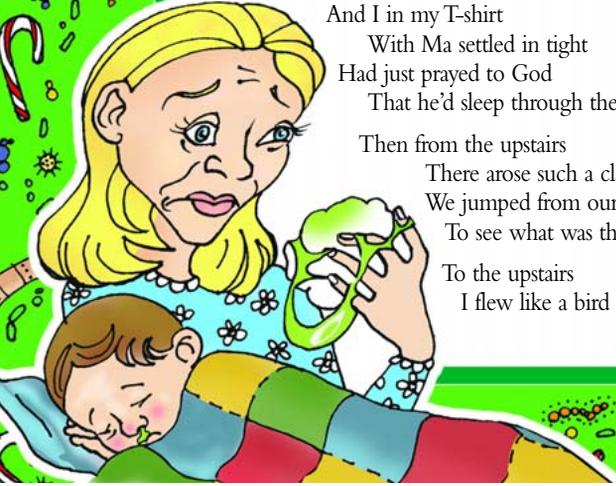
"He'll go back to school
He'll learn and he'll play
He'll get his life back
He'll have a great day!"

So I turned heel for bed
And I felt like a jerk
But I needed my rest
Before going to work

Ma stayed with her son
Stroked the hair on his head
And when he fell back to sleep
She came back to bed

And she said with a smile
As she turned out the light
"Healthy Holidays to all
Gamma will make it all right"

Illustration by Caroline Carlson



For the Love of Teddy

By Dan Bennett



For the infusion patients at UCLA Medical Center's Christmas of 2005, it was Spiderman to the rescue. Not to mention Barbie, the Beanie Babies and a teddy bear or two.

The occasion was the stuffed-animal project organized by Ian Riley, a then-10-year-old Lancaster, Calif., infusion patient at UCLA Mattel Children's Hospital. No one likes getting stuck with a needle and hanging around the hospital for hours, and Ian understands that as much as any child with a chronic disease.

But, unlike just any child, Ian didn't just put up with the situation; he took action. He felt a need to help fellow young infusion patients be a little more comfortable during their treatments, so Ian started collecting stuffed animals, something most kids can relate to.

"This was something to make the kids feel better," says Ian, now 11.

Ian knows from experience the occasional need for a little extra tender loving care, having been diagnosed three years ago with a primary immune deficiency disease.

"Ian used to go to the procedure area with a stuffed animal," said his father, Chris. "It gave him some comfort. He started thinking it might help other kids feel better."

Ian's mom, Valerie, says the project started out small and then just grew.

"Ian started to save and buy new stuffed animals," said Valerie. "He thought it would help the kids who were scared or who cry during infusions. He then broadened that and asked the hockey club he plays for if he could involve those on his team. Then it just expanded from there."

Ian began to make group presentations and write letters. Chris and Valerie began sorting the animals, and, by the time the collection went past 700, they had a room in their home devoted entirely to the collection.

By Christmas 2005, Ian had collected 738 new stuffed animals and made a special delivery to UCLA for the holiday season.

"These are brand-new stuffed animals, mostly purchased by the parents," Chris said. "All of the families really got behind this idea."

"Even one of the high school kids asked for one," Chris said. "Stuffed animals make kids happy."

Children who were receiving infusions at Children's Hospital were each given a stuffed animal, and several were sent over to children who were participating in a program at the University of Southern California.

"For Ian, this was an opportunity to do something for someone else," Chris said. "He doesn't like to think of himself as different from the other kids receiving infusions. It was just a way for him to give back."

The initial project involved numerous hockey teams throughout Southern California, and, according to Valerie, Ian is hoping to make this an annual campaign with the teams' support and any other help he can get from people who appreciate a good teddy bear.

"I want to do this for a long time," Ian said. "The kids are my friends." ■

For more information, please contact Ian's mother at valerie_riley@hotmail.com

A New Feature From IG Living!

IG Reimbursement

Q&A



IG Living is pleased to provide this new feature for our readers. If you have an IG reimbursement question, let us know!

Pat asked if Medicare pays for intravenous immune globulin (IVIG) homecare.

Yes, Medicare does pay for IVIG in the homecare setting, but your diagnosis determines if you are covered under Medicare Part B or Part D.

If you have a primary immune deficiency disease (PIDD), you are covered under Medicare Part B, but only for the IVIG product itself and *not* for any nursing services or the medical equipment needed to deliver your IVIG.

Homecare companies are covered at the same reimbursement rate as the physicians and the hospital out

patient settings, but again only for the IVIG itself.

It may be difficult to find a homecare provider that can serve you, unless you have a secondary insurance policy—that is *not* a

Medigap policy. Your secondary insurance should cover nursing services and medical equipment. So, if you are looking into homecare, be sure to tell prospective homecare providers that you have such secondary insurance.

If you have a diagnosis other than PIDD, you may be covered under Medicare Part D. Many patients with chronic inflammatory demyelinating polyneuropathy (CIDP), myositis, myasthenia gravis and other diseases are able to receive their IVIG in the homecare setting under Medicare Part D. Part D reimbursement for IVIG is more favorable than Part B. It is important when choosing a Part D plan to make sure that your disease is covered and that your brand of IVIG is on the provider's formulary.

Chris asked about becoming eligible for Medicare in January, due to her being deemed disabled, and she is concerned about the Medicare reimbursement problems. Chris' dermatomyositis is in remission, but she is worried about relapsing and needing IVIG again. How can she prepare for this possibility?

When Chris chooses her Medicare policies, she should make sure that she chooses Part B and considers choosing Part D.

Like many other patients on Medicare, Chris will have difficulty finding a provider who can afford to provide IVIG under the current Medicare reimbursement system. However, Medicare Part D does reimburse better than Part B, and Chris may be eligible under Part D. In the past, Chris has done well on IVIG without any side effects, which can make her a good candidate for homecare. Also, she should be prepared to show Medicare all of her documentation that other therapies have failed and IVIG was the one therapy that put her in remission. ➤

Michael asked what he can do about his employer's having recently switched insurers to a new company that is denying his claims for IVIG to treat his dermatomyositis. Michael had previously been covered by Medicare and two private insurers, prior to the new insurance company's denying his claims.

First, you must *always* appeal a denial from your insurance company within the defined time period. Most people do not appeal denials, but, if you do—and if you keep pursuing it—in most cases, you will succeed. Make sure that when you sign up with a private insurance company that you request a caseworker. You should not be calling an 800 number and talking to a different person each time. A caseworker will typically have a medical background and should become familiar with your case.

Michael needs to determine what the insurance company is actually denying in his Explanation of Benefit (EOB) form(s). He may need to appeal more than one claim, and, if Michael works with a caseworker, he or she should be able to help Michael figure out exactly what is being denied and what documentation is needed to challenge the denial.

Resolution: Michael reports that the support materials provided for his appeal—and his persistence—have resulted in a successful appeal: He received a letter from his insurer stating that his past and future IVIG treatments will be covered!

.....

Always be prepared to submit copies of medical literature to support the use of IVIG for your disease state. A second opinion from a well-respected physician in the field can help as well.

If Medicare covers IVIG for your disease state, which it does for Michael's dermatomyositis, then show a copy of that coverage to your private insurer: Private insurance companies typically follow Medicare's payment and coverage determinations.

Most important, for diseases such as myositis, myasthenia gravis, multiple sclerosis and others, you must document that you have tried other therapies first, that they have failed, and that IVIG is the therapy that works for you. ■

Do you have an IG reimbursement question? Send it to editor@igliving.com or call the editor at 800-843-7477 x1143.



To Thine Own Self Be True

By Ever Fecske

Vanity—I never realized before the different ways I can be vain. I wouldn't call myself a vain person but I do have my moments, especially since being diagnosed with a primary immune disease. It goes deeper than just wanting my shoes and purse to match, or spending an obsessive amount of time on that one curl that just won't lie flat. How do I explain the bruises from my infusion? How do I cope with the changes my body is going through?

Let me tell you about my latest fight with vanity. For the past five months I have been on 40 milligrams of prednisone a day, trying to treat a lung disease that seems to have a mind of its own. This is the third time that I have been treated with prednisone for various syndromes, so I was far from thrilled to learn I would have to go through the pudgy, ugly syndrome again. For those of you who aren't aware of prednisone and what it does to you, let me fill you in.

Prednisone is a steroid. A lot of people like to call it "the miracle drug," and it truly is. It has saved my life three times now, so don't think I'm not grateful. I couldn't be more grateful, but I am also on prednisone, so please excuse me for being a little crankier and more cynical about it than I should be.

The problem is, it's really hard for me to believe that I could gain 30 pounds in three weeks, but sure enough, the scales never lie. Not only did I gain weight, but I blew up like a balloon about to burst. When your body goes through these kinds of drastic, rapid changes, you never really adjust. My face has taken a shape that I didn't know was possible—it would fill a fish bowl. Sometimes I look

in the mirror and all I can do is laugh, or sometimes cry, depending on my mood.

Mood swings are part of the side effects of prednisone. I feel angry, then grumpy. I truly don't recognize myself, and I think that is the most difficult thing. I am also plagued by severe joint and muscle pain, headaches, fatigue, muscle loss—the list goes on and on. But through it all my vanity hurts the most. I want my body and face back to what they were, but I can't have that. Not right now anyway. So how do I deal with it? How do I give up my vanity and see beyond what is on the surface?

When I am thinking logically about my illness, I couldn't be more patient and understanding. I can always see the light at the end of the tunnel. I know time will heal me. I also know what I am going through right now will be best for me in the long run.

I acknowledge that I will be on this medication for months and I will adopt the side effects as a part of my lifestyle. When I have leg cramps, I will take a painkiller. When I am ravenously hungry, I will eat—whatever I want! I will be good to myself in every way, to allow myself to indulge my hunger and my anger as a way of making up for my vanity!

When I feel angry, sad or frustrated, I wish my intellect could make me feel better, but no matter how much I tell myself this is what is best for me, I can't seem to rid myself of these feelings.

My biggest problem with my vanity is running into people from school, or from the past, whom I haven't seen in a while. It's all over their faces: What did she ➤



do to herself, poor thing? She sure put on a lot of weight.

And wouldn't you know, in the last four months I have run into more people I went to high school with than in all the years combined since I graduated. It's almost as if my lesson is to forget about my outward appearance and realize that beauty comes from within. Although I know this is true, I still feel the need to start off every conversation with "Hi, it's so good to see you. It's been so long. I see you are surprised by how I look. Well, I'm not fat; I'm on prednisone."

Instead, though, I find myself doing everything I can to avoid meeting anyone I haven't seen recently or who doesn't know my situation. There is no need for me to feel more awkward than I already do. I know this is wrong, but I feel so much better doing what feels comfortable.

I have turned into an insecure, uncertain person who hates the way she looks and feels. I know people perceive that I feel badly about myself by the way I talk to them, which perpetuates the awkward feelings. I admit it: When I am dealing with these emotions, I start thinking irrationally. My sense of self-worth is flushed down the toilet. My mind is suddenly flooded with self-doubting questions. Do they think I just let myself go? Are they talking about me right now?

It's even gotten to the point that I am insecure around my family and my boyfriend. Deep down, I know they understand what I am going through, and they will stick—and have stuck—by my side 100 percent, but that irrational side of me always seems to come out, too. I ask myself: Why does my boyfriend stay with me, when I feel so undesirable? Does my family think I am lazy?

Do they think I am crazy?

How absurd to ask myself so many self-destructive questions and doubt the character of the ones I love. And all because of the way I look!

We have all heard "It's what's on the inside that counts." We were taught it in school, in children's books, and many times it was the central lesson in Disney movies. While I do believe this saying is true, I also believe, since being diagnosed with an immune deficiency and a lung disease, that my insides don't really count for much!

So, instead, I would like to change that saying to "It's what's inside our minds that counts." It's our thoughts that control our feelings and our actions and the way we view ourselves. When we are mentally healthy, the way we look has nothing to do with our intelligence, our opinions, our compassion or our experiences. This is the true substance of life—not what we see in the mirror, but what we do for others.

We have so much to give, so let's not dwell on what we have no control over. Based solely on our experiences, we have an understanding and an empathy not many have. Be forgiving. And avoid mirrors.

In the past, I took my looks for granted. I always thought I was fat or my hair was too short or my nose was too big. I was never satisfied with myself; there was always something I wanted to change. Not anymore. After having experienced a total transformation, and dealing with the discomfort of it—not only physically but socially—I can't wait to be back to the old imperfect me, and this time I will appreciate what I have. ■

Sites of Care

Josh Harrison was at his computer, playing World of Warcraft,* when he messaged the person he was playing with that he had to get up and go for a minute.

"Where are you going?" asked the other player.

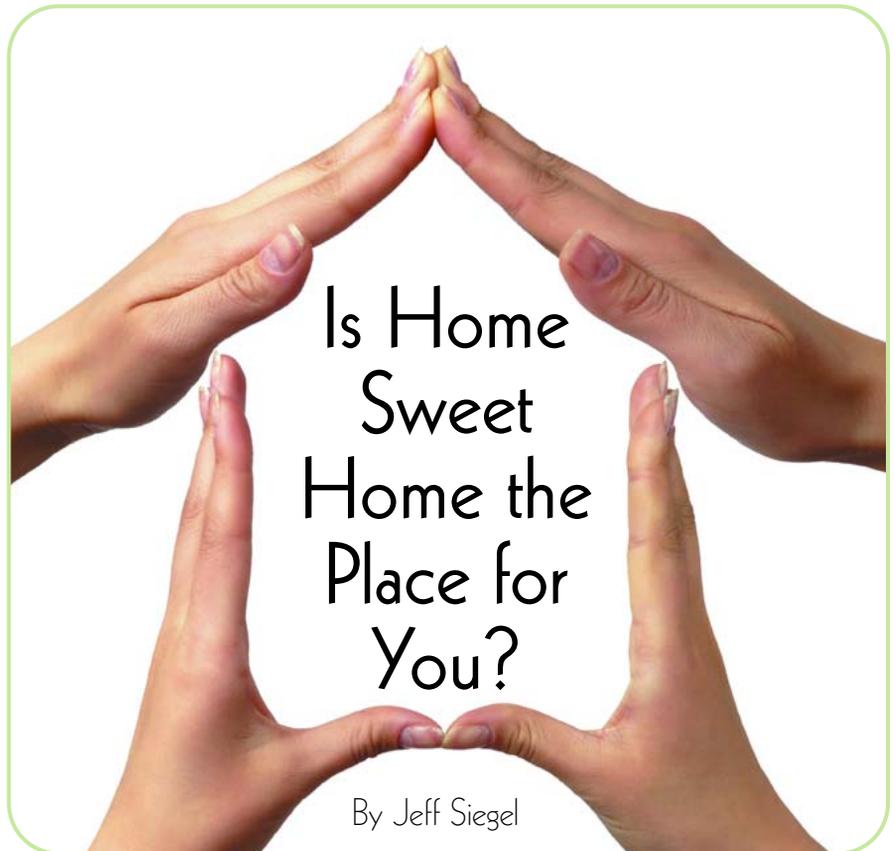
"Oh, I have to go do something for my infusion," said Josh, a 17-year-old in suburban Seattle who has X-linked agammaglobulinemia, a primary immune deficiency. And with that, he turned away from the computer and did what needed to be done, returning to the game a few minutes later.

And it's just part of a day in the life of someone who receives their immune globulin (IG) infusions at home. Many in the IG universe are hospital outpatients or visitors to infusion suites or doctor's offices. But a growing number are doing it at home—whether it's more convenient, whether they don't feel comfortable in a clinical setting, or whether they just think it's best for them. By one estimate, as many as 1 million people across the United States may be receiving infusions at home.

"It's not really that big a deal anymore," says Josh, who has been getting infusions for most of his life. "I can use the computer, I can watch TV or whatever. The nurse takes the vitals, and then I can take the IV out. I'm really not squeamish about it."

Yet, having said that, doctors, homecare experts, and even patients acknowledge that home infusions are not for everyone. The option may be growing in popularity, thanks to improved technology, physicians more willing to recommend it, and an emphasis from the insurance industry to shift patients out of hospitals and doctor's offices, if possible.

"But there are people who shouldn't do it," says Jordan Orange, MD, who teaches at the University of Pennsylvania's Medical School and is on staff at Children's Hospital in Philadelphia in the division of immunology. "They might be more subject to adverse events and could need direct and expert supervision. But the majority who



receive infusions without any difficulty, those people are afforded a choice with homecare."

Infusing at Home

An infusion is pretty much the same wherever it's done, whether it's the equipment, the drugs or the procedure. After all, an IV is an IV, regardless of the setting.

What's different—and this is a crucial difference—is that, at home, the patient is in charge of the procedure. That means lining up the equipment, ordering supplies, and, in some cases, actually performing the infusion.

"Now, for us, things have gone smoothly," says Catherine Beal of suburban Cleveland, who does all of that for her 7-year-old son, Jacob, a primary immune deficient patient who receives his infusions subcutaneously. "But we're not the first family our immunologist switched to home, so things were in place for us. We knew what to expect."

Typically, people who want to do home infusions must understand:

- **The role of their specialty pharmacy or homecare service.** These companies—some local, some ➤



regional, and some national—provide the equipment, drugs and supplies as well as the nurse who does the infusion, monitors the patient's vital signs, and is in the home if there is an emergency. Beal says that next to a supportive doctor, a first-rate specialty pharmacy is a must for home infusions. One note about equipment: It's much smaller and takes up less space than ever before. The Harrisons keep everything they need in a large Tupperware-style container that slides under a bed.

- **What their insurance will and won't cover, plus the various network and out-of-network benefits and limitations.** Generally, though it's not a hard and fast rule, insurance companies don't mind seeing infusions done at home (part of their philosophy that the more healthcare provided outside of a hospital, the less it's going to cost). But each insurer is different, and anyone interested in home infusions needs to understand their coverage thoroughly.
- **How it's done.** Who will infuse the drug? Who will take out the needle? Where in the house will it be done? When will it be done? What equipment is needed? Where will it be stored? What happens if there's a power failure during the infusion, and the pump stops working? If something goes wrong, where is the phone? Who is supposed to call 911? Some of these questions can be answered by the physician or specialty pharmacy. Some can best be answered by talking to parents and patients who already do home infusions.

"What we're seeing is the market continue to grow for this," says Katherine Werner, vice president, professional affairs, for the National Home Infusion Association in

Alexandria, Va. She estimates that there are 4,000 homecare providers in the United States, with an average of 250 patients each (and that number is probably conservatively low).

"And there is still a lot of growth possible for this market," says Werner. "As you see more biotech products come out that require infusions, you're going to see more acceptance of home infusions. We've come from where we've had a hard time convincing physicians and payers to pretty much that it's acceptable and safe."

Making the Choice

Who is a candidate for home infusion? That requires agreement between the physician and the patient, and the patient's parents, if necessary. It's not for everyone. The first question to answer, say doctors, experts and patients, is whether the patient wants to do it. If not, none of the other advantages—convenience and flexibility foremost among them—matters. Some people, says Dr. Orange, prefer doing it in a hospital or infusion suite—whether for the social experience or because they feel safer there than having the infusion at home. "It's a quality of life issue," he says, "and there are personal reasons for what people do."

One key resource for evaluating the option of homecare, says Orange, is the IVIG toolkit, available at the American Academy of Allergy, Asthma & Immunology website at aaaai.org/members/resources/initiatives/ivig.stm. In addition, he recommends that anyone interested in home infusion check out the AAAAI site-of-care guidelines for administration of IVIG, which are part of the toolkit.

The second consideration is the patient's health.



Typically, says Werner, home infusion is used only by people with chronic diseases like primary immune deficiencies or other immune system-related illnesses. Someone who needs infusions only for a relatively short period isn't a good candidate, since the effort to set up the home infusion system is greater than the benefit they'll get from it.

Additionally, the patient should be able to handle the overall infusion process well. This means not only that they don't have any serious adverse reactions from it, but that they're comfortable with it, understand it and know what's required to do it.

"I think the age of the child is important," says Carol Harrison, Josh's mother. "A teenager is going to have less trouble at home than a toddler. It's about temperament. Some kids just don't do well with that sort of thing."

Seven-year-old Jacob Beal is so comfortable, in fact, that he does his subcutaneous infusion while he is sitting in class. His mother puts the needle in before he leaves, and the pump, about the size of a large billfold, is in a fanny pack around his waist. When the infusion is complete, Jacob removes the needle. Plus, his mother says with a laugh, when someone asks Jacob what he's doing, her son can describe the process accurately and precisely. "We've worked hard to help Jacob understand exactly what's going on," she says.

Even then, there are caveats. The school administrators know what Jacob is doing, and Catherine works in the same building. Whenever doing a home infusion (and especially if there isn't a nurse handling the infusion), make sure someone else knows what's going on, when the infusion is taking place, and how long it should take. Older kids who do it themselves have a tendency to not

want to tell anyone what's going on, which can lead to problems if something goes wrong. Anyone who does it themselves must realize they aren't soloing.

Which is the case in point. If someone doesn't want to go to that much trouble, then they shouldn't do an infusion at home. Says Catherine Beal, whose son has had home infusions for three years: "A lot of it is because of our schedule. I'm a working mom, and now that Jacob is older, he needs to be in school."

Scheduling, says Carol, also has a lot to do with why Josh does his infusions at home. Interestingly, when he started infusions in the late 1990s in the San Francisco Bay area, it was less expensive to do it at home than as an outpatient. It really has never been a problem for her son. "Overall, it really went very well," she says. "He was quite a good patient. By the time he was 3, he had learned it was in his best interest to cooperate."

Which is something Josh still understands. Or else he wouldn't be able to do it as well as he does. Save for drinking extra fluids to prepare for the IV, his home infusion doesn't seem to be that much of an inconvenience, he says.

And his mother agrees. "People are really interested in it," Carol says. "The ones we've talked to say it's a positive thing. And trust me—the stress level goes way down when you're doing it at home. It beats driving all that way and then sitting in the office. The benefits outweigh the small problems."

And besides, Josh gets to play World of Warcraft while infusing. ■

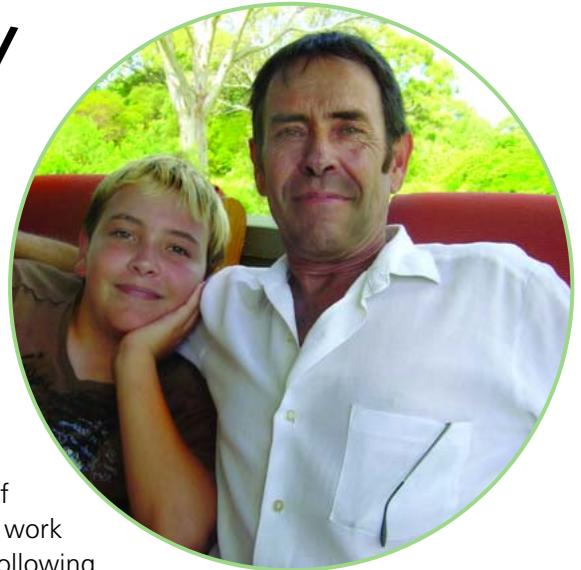
* World of Warcraft is a registered trademark of Blizzard Entertainment Inc.

Everyone Has a Story and This Is Graham's

By Carol K. Miletti

“We all have big changes in our lives that are more or less a second chance.”

Harrison Ford, actor



Graham with his son, Chris

According to Graham Hyde's family, he spent most of his first two years crying.

Now 50, Graham sees the crying “as a sign that I already knew what my life was going to be like and didn't want to stay.” Growing up in New Zealand, it seems he was always dealing with some illness. He began to have recurring ear, nose and throat infections at about 6 years of age. By the time he was 14, he had his first of many pneumonias and hospital stays. He was averaging four bouts of pneumonia per year.

Graham spent much of his life asking “Why me?”

This is a common question among chronically ill patients, but Graham seemed to dig a little deeper looking for the answer. Despite his illness, he found a way to have a career that was also his hobby. He became a qualified motor mechanic with a passion for race cars, but an injury left him out of work and in a cast for three months. He subsequently became ill after receiving a flu vaccine, and the medical staff informed Graham that there was no hope of survival. He can still recall the struggle of trying to breathe and a near-death experience that he refers to as “the light at the end of the tunnel.”

Graham did survive and he has a distinct memory of being sent back with more work yet to be done. However, following this, Graham was diagnosed in 1992 with hypogammaglobulinemia, or common variable immune deficiency (CVID).

During the next few months, Graham began a schedule of intravenous immune globulin (IVIG) every three weeks. He decided to move to Australia, where the climate was better. And he knew he had to work on his attitude as well.

“I have had a lot of issues with my anger toward the health system in general, taking so long to [diagnose] me, and yet I have to thank them and the IVIG that keeps me on this planet today—odd situation to be in.”

Graham has since become a volunteer counselor for a group called Lifeline. He also trains others to do this work. He can't believe how profoundly his volunteer job has changed his life. The combination of his work and his near-death experience has helped him to find himself spiritually. He knew it wasn't his time to go, but he didn't know why he was given more time. He feels he now has the ability to have a profound effect on the people around

him. This work has given him a reason for living.

Not that he didn't already have a good reason: His son, Chris, 13, just happened to be born on the same day as Graham, who was born on the same day as his father! Chris is very aware of the condition of his dad's health and helps as much as he possibly can. But they both feel frustrated when Graham doesn't have the energy to ride a bike or kick a ball around. They have had to find mutual ground in quieter pastimes such as fishing and racing radio-controlled cars.

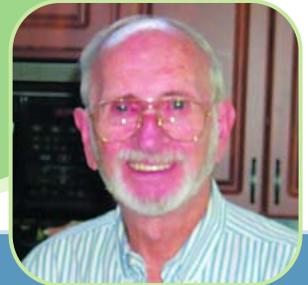
While Graham still feels compromised physically and often feels scared, he says it is much better than before his diagnosis. As for his future? He used to take one day at a time, but lately, he has been able to look further ahead. “I want to be just like me again!”

And Graham hopes to encourage others. “Have dreams and aspirations... never give up on realizing them, no matter what.” ■

Let's Talk!

By Shirley German Vulpe, EdD

For this fifth column of the Let's Talk series, I interviewed Seymour Fuchs, a gentleman from Florida with a primary immunodeficiency. Medicare had denied payment for his immune globulin infusions.



Shirley: Can you tell me a little bit about your illness?

Seymour: Sure, I am a cancer survivor, and I have renal artery insufficiency caused by a blockage. Therefore, I have damaged kidneys and have a lot of swelling in my lower legs. These illnesses were medically under fairly good control. However, I was having very frequent colds with sore throats and coughs. They would last up to three weeks. Some would turn into pneumonia. I would just get better, and then I would get sick again.

My physician thought there may be a reason for this and decided to investigate. One of the tests he did was for my immune globulin levels. The IgG level turned out to be very low.

Shirley: What happened next?

Seymour: My physician suggested that I have infusions of IVIG. I agreed to this. I received four and a half units on a monthly basis. First, I went to the doctor's office. Then we discovered that Medicare would not pay for either the medication I was receiving or the cost to deliver the infusion in the physician's office. Medicare said that they would pay for a different brand of IVIG, not the one my doctor ordered.

My doctor said I could not receive any other brand, as my kidneys were damaged and any other brand would damage them further. Then I went to the hospital to receive

my infusions. I was still receiving the brand of IVIG my doctor said I had to have. Medicare continued to refuse to pay for my infusions.

Shirley: Are you on Medicare because of your age or because of your disability?

Seymour: Because of my age.

Shirley: Do you have other health insurance?

Seymour: Yes, I have other coverage to pay my co-pay. It, however, only pays if Medicare pays.

Shirley: So what happened next?

Seymour: My doctor found out about... the possibility of my giving myself the IG subcutaneously (SubQ). We submitted an application to Medicare to have me receive my IG SubQ. It was approved immediately for the specific product I need. I was trained and started giving myself IG SubQ. Initially I was giving it to myself five times a month. Four full doses and one-half dose.

Shirley: That has changed?

Seymour: Yes, my IgG levels improved dramatically. They are 1160 now. So my doctor said I could cut back and only do SubQ four times a month. In addition, I no longer get colds, coughs, sore throats and pneumonia.

Shirley: Well, that is certainly wonderful and a great relief to have what you need paid for by Medicare.

Seymour: Certainly is! 🍷

For More Information

Medicare, www.medicare.gov, is a health insurance program for people 65 years of age and older, some disabled people under 65 years of age, and people with end-stage renal disease (permanent kidney failure treated with dialysis or a transplant).

For general Medicare information, ordering Medicare booklets, and information about health plans, contact 800-MEDICARE 24 hours a day, seven days a week for assistance. English and Spanish-speaking customer service representatives at this number can answer questions about the Original Medicare Plan and provide up-to-date information regarding the health plans available in your area.

Prescription Drug Coverage:

Since January 1, 2006, everyone with Medicare, regardless of income, health status or prescription drug usage has had access to prescription drug coverage through Medicare Part D.

The Immune Deficiency Foundation,

www.primaryimmune.org, provides some assistance to patients and physicians with IVIG access problems. For more information, visit the IDF website or call 800-296-4433.

Food Safety

Home for the Holidays

By Jessica Schulman, PhD, MPH, RD

The holidays are an opportunity for celebrations and feasts. Yet that stuffed turkey, cream pie or homemade ice cream, while looking and smelling fabulous, can be a danger to your health. Even the most well-meaning hosts can make food-handling blunders, inadvertently offering foods that can cause food-borne illnesses. Among groups with special health concerns, it is essential to practice safe food handling techniques when entertaining, during the holiday season and throughout the year.

Thus, in the spirit of the holidays, this article will (1) describe why there is a need to increase awareness of food safety principles, and (2) offer basic food safety tips that can be used to reduce risk of food-borne illnesses. Consider clipping out these resources and placing them on your fridge, or giving them to anyone who cooks for you during the holidays. For those who are vulnerable to infection, preventing food-borne illnesses—and promoting good health—may be the greatest holiday gift of all.

Who's at Risk?

The United States has one of the safest food supplies in the world. Nevertheless, the Centers for Disease Control and Prevention (CDC) estimates that “76 million people get sick, more than 300,000 are hospitalized, and 5,000 Americans die each year from food-borne illness” (CDC, 2006). About one in four reported outbreaks are due to improper food handling practices at home. Today, preventing food-borne illness is a major public health challenge, and this is particularly relevant for at-risk groups, including people who live with weakened immune systems, pregnant women, young children, elderly and cancer survivors.

What Do I Need to Know? Fight BAC!®

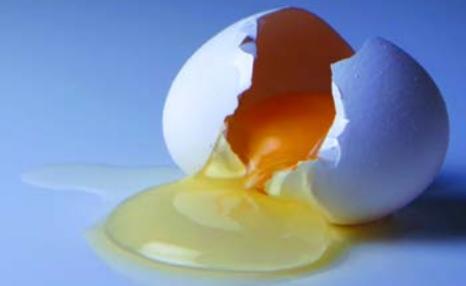
To reduce the rate of food-borne illnesses in the home, the Partnership for Food Safety Education developed the Fight BAC! campaign (as in Fight BACterial), bringing together industry associations, consumer and public health groups, and governmental organizations to provide guidelines for safe food-handling. Safety precautions are organized into four easy-to-use steps that will help everyone to reduce the risk of food-borne illness:

Clean: Wash hands and surfaces often.

Separate: Don't cross-contaminate.

Cook: Cook to proper temperatures.

Chill: Refrigerate promptly.



Share these steps with those you love, for a safe and low-BACteria holiday.

1. **Clean:** With all due respect, please disinfect!

True or False? It is safe to assume that most people follow food safety principles.

False. In a study to see how well people generally follow the Fight BAC! guidelines (published in the Journal of the American Dietetic Association; Anderson, Shuster, Hansen, et al., 2004), researchers videotaped 99 people in their homes while they prepared their meals. Most of the participants did not follow the guidelines. Only one-third of the participants washed their hands with soap and only one-third used a clean kitchen surface during food preparation.

Tips:

- Wash hands with warm, soapy water for at least 20 seconds before and after preparing food. Remind friends and family to do the same!
- Replace sponges every 1 to 2 weeks.

- Keep sponges and dishcloths clean (e.g., submerge in diluted non-scented bleach [1 tsp bleach: 1 quart water] for 1 to 2 minutes. Only bleach will kill both viruses and bacteria.
- Consider using paper towels to dry hands and clean kitchen surfaces.
- Keep pets away from the kitchen, eating surfaces and equipment.
- Clean the inside walls and shelves of the refrigerator monthly with hot, soapy water; then rinse. Clean up spills immediately.
- Rinse fresh fruits and vegetables under cool running water, including those with skins and rinds that will be sliced, and rub firm-skinned fruits and vegetables with a clean brush or coarse paper towel. Be sure to clean peels and rinds as well; microorganisms from the outside of the food can spread to the inside section when the fruit or vegetable is cut or peeled. Remove bruised or damaged areas.
- People with weakened immune systems should avoid eating alfalfa sprouts and prepackaged salad products until their safety is assured.

According to Martin Wiedmann, DVM, PhD, associate professor, Department of Food Science, Cornell University, "While washing leafy vegetables might reduce *E. coli* numbers, it cannot completely eliminate *E. coli*, since *E. coli* may sometimes be found inside plants and not just on the surface. In general, it may thus be advisable for people with severe immunosuppression to avoid any raw leafy vegetables."

When in doubt, throw it out!

2. **Separate:** Use a clean serving plate, don't cross-contaminate!

True or False? Unwashed hands are the most common cross-contamination agent.

True. In the study described above, Anderson et al. reported that "nearly all subjects handled food in a manner that caused cross-contamination" (J Am Diet Assoc, 2004).

Tips:

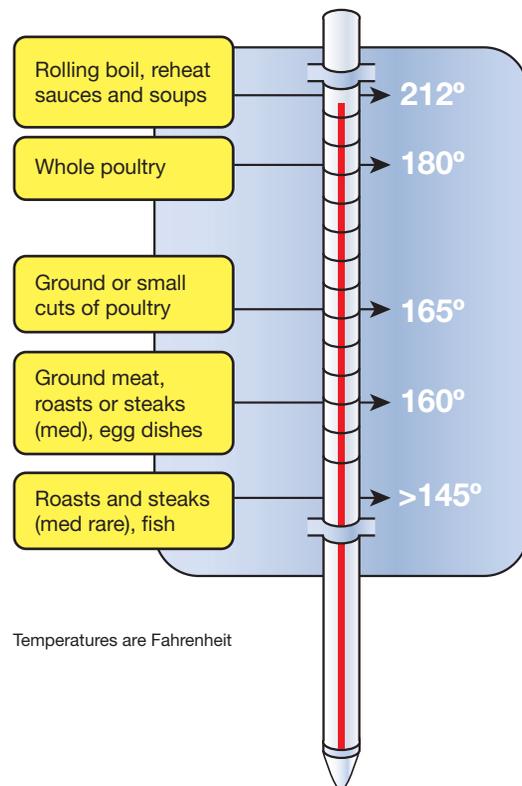
- Wash cutting boards and kitchen surfaces with hot, soapy water after preparing each food item.
- Cut vegetables first, then raw meat and poultry.
- Avoid cross contact, or contamination, by washing all surfaces that have been in contact with raw meats, poultry or eggs before reusing.
- Mix foods with utensils, not hands.

- Wash your utensils, or place them in the dishwasher, after preparing each food item and before you go on to the next food.
- Avoid coughing or sneezing over food. A person with skin infection or infectious disease should not prepare food. If it must be done, use gloves and a mask.
- Never place cooked food on a plate that previously held raw meat, seafood, eggs, etc.

3. **Cook:** Keep hot foods hot!

True or False? If a hamburger is brown in the middle, it is done.

False. Looking at the color and texture of a food is not an adequate method of determining safety. You have to use a food thermometer to be sure. According to the USDA, about one out of every four hamburgers turns brown before it reaches a safe internal temperature. Ground beef should be cooked to at least 160°F (lift the patty out of the pan and insert the thermometer sideways). ➤



This chart has been adapted for home use and follows the consumer guidelines for Fight BAC!®. Individuals with severely weakened immune systems may require slightly different guidelines. Talk with your healthcare provider for assistance.



Tips:

- Seeing is not believing: Use a meat thermometer to test the internal temperature of meats and poultry. Insert the thermometer into the thickest parts of the meats. Food is safely cooked when it reaches a high enough internal temperature (160°F) to kill most “bugs” that cause food-borne illnesses.
- Cook whole poultry to at least 180°F. Small pieces of poultry should reach a safe minimum internal temperature of >165°F.
- Cook ground meat, where bacteria can spread during grinding, to at least 160°F and ground poultry to 165°F. Slightly higher temperatures (>165°F – 180°F) will produce well-done meats and further reduce risk.
- Cook roasts and steaks to >145°F. Medium well is 160°F and well done is 170°F.
- Cook fish to >145°F and until the flesh is opaque and separates easily with a fork.
- Cook eggs until the yolk and white are firm, not runny. Don’t use recipes in which eggs remain raw or only partially cooked. Cook casseroles, sauces, custards, etc., to at least 160°F.
- Reheat leftovers to 165°F. Reheat sauces, marinades, soups and gravy to a rolling boil (212°F).
- Avoid pockets of uncooked food in the microwave. Cover food, stir and rotate for even cooking.
- Crockpots and warming trays should be 140°F or warmer.
- Discard or avoid anything left out for two hours or more.

4. Chill: Cool Rules

True or False? Boiling hot chicken soup can be cooled to room temperature for a few hours and then placed in the refrigerator.

False. During the time that soup stands cooling at room temperature, bacteria that cause food-borne illnesses could have multiplied enough to cause gastrointestinal discomfort or food-borne illnesses. Always refrigerate leftovers promptly.

Tips:

- Use shallow containers to help foods cool faster.
- Place an appliance thermometer inside the refrigerator (follow manufacturer instructions).

- Maintain refrigerator temperature: 35°F – 40°F. Check the thermometer at the time your refrigerator compressor just turns on. This is when your refrigerator is at its highest temperature.
- Refrigerate foods quickly because cold temperatures slow the growth of harmful bacteria (e.g., use shallow containers, remove stuffing from turkey and refrigerate separately, etc.).
- Most cooked dishes can keep for up to three to four days in the refrigerator. Reheat thoroughly to 165°F. Throw away dishes that have been in the refrigerator for more than three days.
- Throw out foods with off odors. When in doubt, throw it out!
- Maintain the freezer at 0°F or lower.
- Thaw meat in the refrigerator or microwave. Never defrost food at room temperature. Follow the law when you thaw!
- Keep raw meat and poultry separate from other foods.
- Always marinate food in the refrigerator.
- Do not eat perishable foods that have been left out of the refrigerator for more than two hours on a cool day. Throw away perishables that have been left out for more than one hour on a warm day. Cold foods should be held over ice or cool gel packs.
- Keep cold foods cold!
- Be mindful of your meds: If your refrigerator contains immune globulin or other medications, take extra care when adjusting your refrigerator temperature. Never rely on the number dial (i.e., “1 to 7”). Use an appliance thermometer and consider purchasing a separate refrigerator for medications that require constant temperatures or sterile procedures.

Additional Tips

Food handling slip-ups made in shopping, transporting, storing, preparing or serving food can enable microorganisms to survive and flourish.

Grocery Shopping:

- Do not buy or use items that appear to have been opened; check safety seals, buttons and rings.
- Don’t buy cans or glass jars with dents, cracks or bulging lids.
- Observe expiration dates.
- Select perishable foods last before checking out.
- Do not taste or buy bulk foods from self-service bins.
- Follow label instructions for storing and preparing packaged and frozen foods.

- Treat your turkey with respect:
 - ✓ Buy it last and place it in a plastic bag.
 - ✓ Make room for it in the fridge.
 - ✓ Defrost it in the fridge.
 - ✓ Buy it less than two days before you cook it.
 - ✓ Cook the stuffing separately or place it in the turkey just prior to cooking.
- Take food straight home and refrigerate perishable foods immediately.
- Do not overstuff the refrigerator. Cold air must circulate to keep food safe.
- Store canned goods in a cool dry place for use within a year. Avoid placing them above the stove or in a damp area.
- Put packages of raw meat, poultry or fish in a shallow pan or plastic bag before refrigerating, so their juices won't drip onto other food.

Eating Away From Home for Special At-risk Groups:

- Don't take chances—if you are in doubt, throw the food out.
- Never eat the following items if they are served raw: meat, poultry, eggs, seafood or smoked fish.
- Avoid eating refrigerated pâtés or meat spreads.
- Eat only deli meats and frankfurters that have been reheated to steaming hot.
- Use particular caution at potlucks, buffets or picnics where the food is sitting out.
- Discard egg-based products or prepared cream dishes left at room temperature for more than an hour.
- Avoid homemade ice cream, eggnog and mayonnaise, unless you know it is pasteurized.
- Pass up soft, moldy cheeses such as feta, brie and Camembert, blue-veined cheeses, queso blanco and queso fresco.
- Seek out fresh fruits that can be rewashed or peeled.
- Egg yolks and whites should be solid and not runny.
- Do not eat raw sprouts, including alfalfa sprouts.
- Do not use herbal infusions or supplements without the supervision of a physician. Some preparations may contain impurities or infection-causing organisms.

Think Before You Drink:

- Where the water supply may be suspect, boil it or use bottled water.
- For individuals living with immune deficiencies, boil all drinking water and use bottled water.
- Look for packaged juice that has been pasteurized. Be cautious with beverages that are kept in the refrigerated section of the store, because they rely on the temperature to keep bacterial contaminants down.

- Avoid fresh squeezed juices that are sold by the glass such as at cider mills, health food stores, fairs, etc. Warning labels are not required for these products.
- Do not drink raw (unpasteurized) milk or any products made from unpasteurized milk or eggs.

Early Intervention

Even the most cautious people make mistakes, and sometimes even the best precautions are not enough to prevent food-borne illnesses. In these cases, early intervention can make the difference between an uncomfortable few days and a serious problem. Many reactions appear within 72 hours after eating contaminated food, but it is possible for them to occur between 30 minutes and weeks later. You should consider the possibility that you may have a food-borne illness if you experience any of the most common symptoms, which include abdominal cramps, diarrhea, head- and muscle-aches, fever, weakness and vomiting. Very young children may present with these or other symptoms. Infants, for example, may show signs of constipation and slowed eating as a first sign of clostridium botulism poisoning. Contact your physician if you have any of these symptoms or suspect that you have a food-borne illness.

By following the guidelines presented in this article, you and your loved ones can minimize microbial contamination, maintain optimal health and enjoy the holiday festivities. Happy holidays! 🍷

Food Safety Information and Resources

Bovine spongiform encephalopathy (BSE)
http://www.aphis.usda.gov/newsroom/hot_issues/bse.shtml

Childhood choking prevention <http://www.ific.org/publications/brochures/index.cfm>

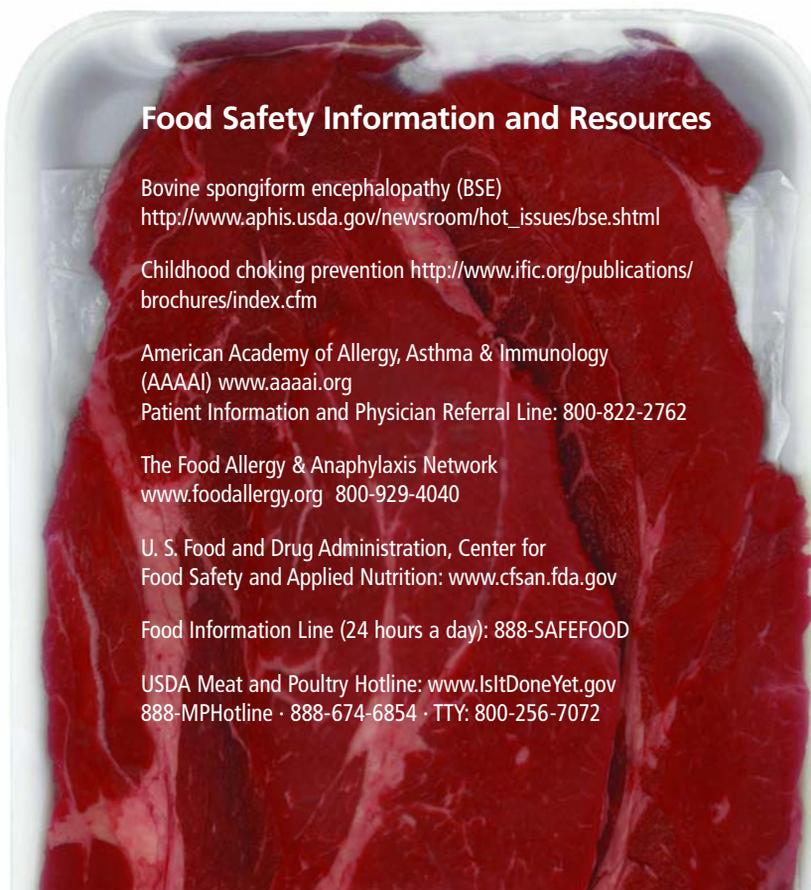
American Academy of Allergy, Asthma & Immunology (AAAAI) www.aaaai.org
 Patient Information and Physician Referral Line: 800-822-2762

The Food Allergy & Anaphylaxis Network
www.foodallergy.org 800-929-4040

U. S. Food and Drug Administration, Center for Food Safety and Applied Nutrition: www.cfsan.fda.gov

Food Information Line (24 hours a day): 888-SAFEFOOD

USDA Meat and Poultry Hotline: www.IsItDoneYet.gov
 888-MPHotline · 888-674-6854 · TTY: 800-256-7072



Interest in Subcutaneous IG Administration Growing

By Kit-Bacon Gressitt

Over the years, most immunodeficient patients have known at least one or two others who infused intravenous immune globulin (IVIG) subcutaneously (SubQ), a use unapproved by the FDA (or “off label”). Although the exact number of patients was unknown, interest in SubQ was growing and the benefits were attractive: potentially fewer side effects compared to IV infusion, more flexibility because infusions could be self-administered at home, and anecdotal reports of less fatigue. The only hindrance to SubQ adoption was the lack of a U.S.-licensed subcutaneous immune globulin (SCIG) product.

“We had a number of patients on SubQ throughout the years,” explained Melvin Berger, MD, PhD, professor of Pediatrics and Pathology at Case Western Reserve University, and a lead Vivaglobin researcher. “We had to use other products, and we sometimes got objections from pharmacies and homecare companies.”

And, many physicians resist off-label use of prescription drugs.

Then, in January, ZLB Behring launched Vivaglobin, an SCIG, in the United States, and it is catching the attention of both physicians and patients seeking improved immune globulin therapy.

Curtis Pease, 23 years old, has a primary immunodeficiency, and participated in the original Vivaglobin trial with his immunologist’s encouragement. “Other than a little itching at the infusion sites,” Pease explained, “it was fine. I was never tired. I never got sick. I felt like a machine!”

But, when the trial was completed Pease returned to intravenous infusions, which he tolerated well, but which left him feeling tired all the time, so he was eager for the product to launch.

“As soon as Vivaglobin was licensed, I got my shipment,” Pease recounted. “Now I infuse myself. I just pinch the skin and stick the needles in. There are more sites, but it’s worth it. My [IgG] trough level is so even—no ups and downs. You just put [the pump] in your pocket and you can go wherever. You’re not fixed to a pole.”

While SCIG has been a revelation for some patients, it is not for everyone.

“The pros and cons need to be discussed with the patients and doctors,” explained Marc Riedl, MD, MS and assistant professor of Clinical Immunology and Allergy at UCLA. “It

does have some advantages compared to IMIG, but it’s not for everybody. I have had some instances of people who switched and actually had problems with SubQ or just didn’t prefer that method of delivery, and went back to IV.”

Still, Riedl sees Vivaglobin as an improvement. “For patients who have had difficulty with IVIG due to side effects or IV access problems, it certainly represents a major improvement. ...Most importantly, it reduces side effects, and an added bonus is it makes patients less dependent on infusion appointments and gives them a sense of having more participation and involvement in keeping themselves healthy. ...Overall, so far, it’s been a success.”

Elaine Hill would agree. She began IMIG infusions in 1996. “I had a lot of problems with minor reactions,” she recounted, “chills, nausea, headaches for days afterward. I had constant problems with breakthrough infections.”

Then Hill heard about Vivaglobin from her immunologist. “I was leery at first,” Hill said, “but he explained to me that it would keep the levels more even, without the peaks and valleys, and I wouldn’t become ill so often, and it would really help with the fatigue.”

After a few months of Vivaglobin infusions, Hill was sold. “It has literally given me back a good week and a half of my life every month. ...I’ve only had one infection. ...It has made a world of difference.”

How many patients experience that difference is yet to be seen, but Berger and Riedl are both prescribing Vivaglobin and they agree there is growing interest in SubQ.

“I think that SubQ will come to be probably more than 50 percent of the primary immune deficiency patients,” Berger said. “Instead of an alternative for patients who have problems ...it should be an option for any patient, evaluated according to its advantages and disadvantages, just as IV should.” ■



Elaine Hill

After my diagnosis of chronic inflammatory demyelinating polyneuropathy (CIDP) in 1998, my physician explained to me what it is. Because I was new to this disease, I had limited understanding, but I knew enough to grasp that my world would never be the same again.

I contemplated moving, changing my name, getting into a new line of work, you name it. However, all those things would not change who I really was and what life had in store for me, and I began to wonder what my real calling was. This question haunted me for seven years, until eventually I realized that CIDP had given me unique gifts that not many people can claim. I started to explore and study them, giving consideration to each.

The first realization I came to was that I was not “different” because of the CIDP, but rather someone who had a special ability to relate to others in the same position or going through a similar experience. I started to question my doctor about different organizations I could join to gain a better understanding of my disease and learn to relate to others in a more informed manner. One of the organizations she directed me to was The Neuropathy Association, based in New York City. It was through them, and with my doctor’s encouragement, that I was able to develop into a neuropathy support group leader.

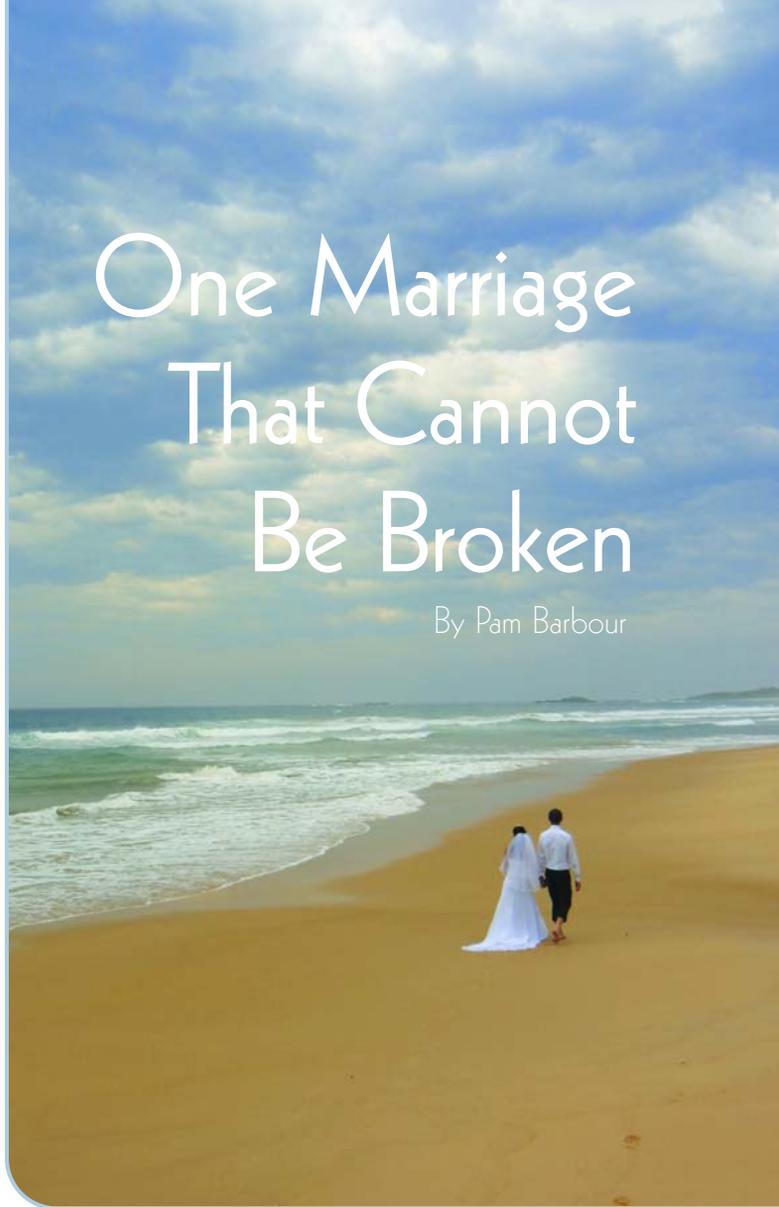
After one month of advertising, I held my first meeting. Through these meetings, I developed many friendships with others who have neuropathy. In turn, they shared with me different experiences, coping techniques and useful advice. The process of networking with others in similar situations had begun. Now, many of these people have started their own neuropathy support groups, to help others as I did. All of this action helped me develop a special way of relating to others in similar circumstances. I felt good.

The second realization came when my husband was laid off. It was time for me to step up to the plate and get a job. I answered an ad in the paper for a reading tutor. I received a call about three weeks later, asking if I would consider an interview. I accepted and soon afterward started the job. I was initially told it was just a summer job, but it ended up becoming permanent.

As time went on, I began to feel useful once again, but I still had this disease, and I felt as if I were married

One Marriage That Cannot Be Broken

By Pam Barbour



to it. Guess what? I was right. I was told it would never go away until a cure is found, but I’ve continued in the tutoring job and I feel wanted and needed. Three years later, I am still tutoring and loving every minute of it, despite my disease.

Finally, I have realized who I am and what I have become: I am an individual with a gift for understanding people with and without handicaps. I have developed more patience than I ever had before. My life has changed greatly. I am more able to adapt to the world around me. I do not fear going alone to public places. I have even learned how to adapt my knowledge of sign language to help me understand other cultures and people. I love to be with people; I love life.

Being married to a disease like CIDP is not so much a burden as it is a life-changing experience. It is a life-changing experience that I am glad I’ve had. This marriage cannot be broken. It will dwell within me forever. ■

The Art of the Gift

By Cheryl Haggard

Webster's Dictionary defines a gift as "something voluntarily transferred by one person to another without compensation." I think back to a moment at my eighth birthday party. I have a warped Polaroid picture of me, a chubby-armed third-grader holding a plastic miniature horse over my head, Dorothy Hamil haircut to boot, as if I were displaying a World Series trophy. The joy of receiving such a deeply coveted item (which sits on my own daughter's shelf some 30 years later) sweetens memories of my childhood, much like my mother's heavenly angel food birthday cakes.

As a mother myself now, raising children with primary immune deficiency diseases (PIDD), "gift" has taken on new meaning. For example, the editor-extraordinaire of this fine publication "gifted" me with a deadline extension for this article. My daughter, Molly, had decided that we hadn't had enough emergency room experiences and consequently broke her arm stuffing herself with chips and salsa, of all things, so writing took a back seat.

"This is perfect, K-B," I squealed. "You extended my deadline to my birthday and I am writing about gifts!" I was giddy with relief.

And now that the gift-giving season is in full swing, I'd like to redefine the word "gift" according to the world of the immune deficient.

The Unexpected Gift

Our kids once believed that my husband, Mark, farmed Band-Aid trees in our backyard (right next to toilet-paper trees). Even the tiniest scrape deserved an expensive adhesive strip that would actually inflict more pain on the patient upon removal than the original owie. Because we began dipping into the kids' college fund to pay for bandages, I decided to stop the innocent slaughter of rubber trees and discovered that duct tape works just fine, even on the nastiest case of road rash.

Recently, our son Caleb was desperately searching for a Band-Aid to ease the pain of his new-shoe blisters. "Hey, Mom!" bellowed my boy from the bowels of my bathroom. "I just found the perfect Band-Aids!"

"Where did he find Band-Aids?" I pondered. "I haven't bought any for months!"

Moments later my headstrong PIDD kid emerged from my bathroom, a couple of sanitary napkins neatly secured with duct tape to the backs of his ankles.

The unexpected gift of laughter, wrapped neatly in duct tape and presented with the toothless grin that only a 7-year-old boy could deliver, was the best present I had received in a very long time.

The Re-gift

The re-gift is the most socially unacceptable form of acknowledging someone's special life event, but by far the easiest on the pocketbook. I have been known to open bank accounts if the free gift for doing so is pretty spiffy (most recently, a really nice duffel bag for my brother). Re-gifting is also the easiest way to de-clutter your closet and avoid holding a yard sale.

Our home healthcare agency recently switched over to disposable and recyclable IV poles for our kids' intravenous immune globulin infusions (IVIG). To my chagrin, the poles were neither disposable nor recyclable. Our trash man refused to take them, saying that medical stuff grossed him out. (Three-day-old diapers didn't? But hey, who am I to argue?) The recycling center attendant thought I had a "really sick sense of humor, trying to recycle used aluminum IV poles." I didn't see the humor in it.

"I know how to get rid of the poles!" I thought. "I'll donate them to Camp Invention!"

My boys were planning to attend Camp Invention this summer, where they would be exposed to the wonderful world of dismantling beat-up home appliances—VCRs, for example—and miraculously bringing them back to life in various forms, such as an outer space creature that spits green goo.

So, to camp they went—with our disposable and recyclable IV poles. On the last day of camp, the parents were invited to learn what the kids had been feverishly working on during the week. It was fun to see how an old radio became the voice of a robot and how a well-loved can opener found new purpose as a futuristic paper shredder. It was really amazing what a bunch of fourth-graders could do with dried-up mini-marshmallows and toothpicks!

As I wandered the halls praising the creativity of my offspring, I was secretly looking for my IV poles. I was really hoping some brainy 10-year-old had turned the silly things into a rocket launcher.

After my search went sour, I finally found the nerve to ask the camp director what happened to my re-gifts.

"Well," she began, "we knew that the poles were used for delivering some sort of IV medication. And because we felt edgy about not knowing what type of medication had been delivered or from what facility they came, we called the number on the poles and the home healthcare agency came and claimed them."

The heat of embarrassment burned my face and I am sure I was as red as a fresh boiled lobster. I left Camp Invention with what was left of my pride and about 50 spent toilet paper rolls duct-taped together, modeling a near-future shop vacuum.

I don't know why the camp director was so worried about my disposable and recyclable IV poles. I was frankly more upset about the toilet paper tubes: I was thinking, "Recycling toilet paper tubes is OK? From what home did these come, and who required that much toilet tissue anyway?"

Of course, when the kids' next infusion delivery came, my home healthcare agency re-gifted me with our disposable and recyclable IV poles.

The Ultimate Gift

Until I began raising kids with PIDD, my three wishes for the genie in the bottle would have been a cruise around the world, the ability to eat anything I want without gaining weight, and maybe world peace. My desires are different now, but my wishes are still found in bottles and delivered by real-life genies.

I believe Caleb would not be alive today if it weren't for IVIG. After five surgeries before age 3, months on IV antibiotics and hours in the hospital, we were at our wits' end. Our ear, nose and throat physician said, "I cannot ethically go into this child's head one more time." We had

run the gauntlet of antibiotics, steroids, nebulizer treatments and nasal washes. We felt in our parental guts that the next infection our boy got would certainly be his last. Caleb was going to die.

Then our brilliant immunologist prescribed what we affectionately call "liquid gold," better known as immune globulin, IVIG. We "rubbed the genie out of the bottle," and got Caleb's life back—and that of his sister and more recently his grandfather.

The ultimate gift that has been bestowed upon our family has been the selfless acts of many who give their liquid gold—their blood, their plasma—so our loved ones can have a fighting chance against infections. And I am reminded every four weeks that were it not for the hours of research and brain power that go into making IVIG, my family wouldn't have the quality of life we enjoy today. To the many who are giving, sacrificing, researching and advocating so our family can be just that—a family—it is with a grateful heart I humbly say, "Thank you."

We have great hope that someday science will catch up with our PIDD families, and we will collectively cheer the words, "We're cured!" Until then, our community has much for which to be thankful. We recognize that each day we live with good health and infection-free is a gift. We have been given so much, without expectation of "compensation" as Mr. Webster defined it many years ago. We have been given the gift of life. ■





Over 52 million people in the United States, and one-quarter of the adult population worldwide, help care for family or friends. With many baby boomers turning 60 this year, that number will keep growing.

That means, if you are a caregiver you belong to a quickly growing group, and *that* means you need to be sure you are taking care of yourself.

“Remember the wisdom of the flight attendant,” advises Dr. Leonard Felder. “Be sure to put the oxygen mask over your own face before trying to help the person next to you.” For some, the first instinct is to help others, not ourselves. But, if we don’t take care of ourselves, how can we take care of anyone else? It’s important to establish a balance between giving and receiving.

The “Daughter Track” is a term coined by Mary Lou Quinlan to describe how many women become caught between two competing priorities of sustaining a career and tending to parents who are living longer and need more help. A second career as a caregiver is not what most of us had in mind. It can lead to a total upheaval of the life we planned: losing out on the perfect job in order to gain flexible work hours, financial setbacks, stress, lack of downtime, no social life, inability to sustain a personal relationship and feelings of guilt that even though you are doing everything in your power, just maybe you aren’t doing enough. Caregivers commonly experience one or more of these symptoms.

Caring for a Parent

Angela Macropoulos is an excellent example of the Daughter Track. You may remember an article Angela wrote for the April-May issue of IG Living, about caring for her mother, who has chronic inflammatory demyelinating polyneuropathy.

“Caregiving is about choices you make to take care of the one you love,” Angela says, and she has made many choices in order to care for her mother. She moved back to her family home on Long Island to be with her mom, who often needs help with decisions, activities of daily living and medical appointments. Angela willingly

forfeited her career path in law and currently works part time as a lawyer and a freelance journalist. This allows her more control of her schedule. Her personal relationships have also been compromised by the choices she has made, although she has a close network of friends she can reach out to. Her friends who have known Angela and her mom the longest understand, unlike most employers, who don’t.

“How do you explain to a traditional boss that you’re dealing with an illness that has no natural beginning, middle or end?” Angela asks.

It is her role in her mother’s healthcare decisions that concerns Angela the most. “The real dilemma in this situation is making the call for treatment and the impact of taking full responsibility for the outcome.” Angela acknowledges that open lines of communication between the doctors, her mom and herself are extremely important.

Caring for a Child

Parents become used to the role of caregiver when kids have any of the numerous childhood illnesses. However, when faced with a chronic illness, life can change dramatically for the parent and the child.

Carol was scared to death when her daughter, Emily, was first diagnosed with a primary immune deficiency disease (PID). Even as a nurse, Carol felt unprepared to deal with the diagnosis. “I didn’t know what to do, and I didn’t know anyone who had it.” Now, Carol thinks about Emily’s health every day and worries about the long-term effects of the illness, yet she wants Emily to have a happy, normal, long life. Carol tries to protect Emily as much as possible, but she wonders at what point she may be overprotective.

Pam’s son, Tim, had already had idiopathic thrombocytopenic purpura and Evans syndrome when he was finally



Everyday Heroes, Our Caregivers

By Carol K. Miletti

diagnosed with common variable immune deficiency (CVID). Pam excused herself from his hospital

room to have a good cry. "I really try hard to keep my emotions in check around Tim." Even though Pam worries about Tim's future, she feels there will be more medical breakthroughs as he ages. Her biggest concern for Tim is insurance—both now and in his future. However, Pam believes in living one day at a time, and she adds that humor really helps.

Carol and Pam both need to be sure they take time to deal with their own fears and stressors, so they can be the best caregivers possible for their children.

Caring for a Spouse

While John and Wendy were dating, John was diagnosed with CVID. He was worried that Wendy would stop seeing him because of his illness, but true love prevailed, and they were married. Wendy did not understand what his disease was at first. She thought it was "something like diabetes, but after attending a national IDF (Immune Deficiency Foundation) convention, it all began to sink in."

Wendy now feels her role is to keep John as healthy as she possibly can. She makes sure he eats well, gets plenty of rest, and insists on his staying home when he is tired. And they have progressed to the point that they are hoping to have a family.

In my own experience, when I became ill, it was hard on my husband, David. "We could no longer do the things we did before," he says, "and while I accept this change, I'm not happy about it. I felt a lot of anger because life was changing." What frustrates David the most is that he can't do anything to make me feel better, and feels there is no end game. What does he miss the most? "The long walks that were the signature of our relationship."

Despite the stress and sorrow associated with my disease, David has become a caregiver who knows how to take

care of himself. He re-energizes himself at work, since that takes his mind off my health situation. He makes sure that he gets exercise and golfs as much as possible.

Caregiving Heroes

Our caregivers are our quiet, everyday heroes, and we need them to be healthy and happy – for our sake and for their own. We need to help them recognize the stress they are under, the physical limitations they may have, and the rest they need. They need to know how much we admire their fierce devotion to us, and sometimes, they need us to give instead of receive. ■

Healthy Tips for Caregivers

- Give yourself permission to be angry or resentful over the situation.
- Focus on the present—not the future or past.
- Practice forgiveness.
- Ask for help when you need it.
- Tend to your own basic needs.
- Blow off steam—get some exercise.
- Nurture yourself.
- Avoid power struggles with the patient and other family members.
- Take time alone.
- Recognize your limits.
- If you need help with family leave benefits, contact www.caregiver.org.
- Laugh and love and hope!

i...Guillain-Barré Syndrome (GBS)

Websites and Chat Rooms

1. The GBS/CIDP Foundation International, www.gbsfi.com, has 23,000 members in 160 chapters on five continents. 610-667-0131
2. The GBS Foundation Discussion Forums provide the opportunity to talk to other GBS patients and learn more about ways to manage the illness: www.guillain-barre.com/forums/.

Online Pamphlets

1. A GBS Fact Sheet is found on the National Institute of Neurological Disorders and Stroke website: www.ninds.nih.gov/disorders/gbs/detail_gbs.htm.
2. The Mayo Clinic has an overview of Guillain-Barré syndrome at www.mayoclinic.com/health/guillain-barre-syndrome/DS00413.
3. The National Institute of Neurological Disorders and Stroke has an information page about CIDP: <http://www.ninds.nih.gov/disorders/cidp/cidp.htm>

Online Peer Support Links

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

...ITP (Idiopathic Thrombocytopenic Purpura)

Websites

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

Online References

1. Idiopathic thrombocytopenic purpura http://en.wikipedia.org/wiki/Idiopathic_thrombocytopenic_purpura
2. Idiopathic Thrombocytopenic Purpura: Michael A. Silverman, MD <http://www.emedicine.com/EMERG/topic282.htm>
3. Immune Thrombocytopenia: Current Understanding and Future Research, Robert S. Mocharnuk, MD: <http://www.medscape.com/viewarticle/459249>
4. Infusion Network Systems Article: The Expanding Use of IVIG provided by ZLB Bioplasma, Inc.: <http://www.infusionsystems.net/article-ExpandingUseofIVIG.html>
5. ITP: Idiopathic Thrombocytopenic Purpura: <http://familydoctor.org/113.xml>

....Kawasaki Disease

Websites

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

...Multiple Sclerosis (MS)

Websites and Chat Rooms

1. The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS. <http://www.nationalmssociety.org/>.
2. All About Multiple Sclerosis provides accurate and comprehensive medical information about MS written in plain English by people living with the disease and its symptoms: <http://www.mult-sclerosis.org/index.html>.
3. Multiple Sclerosis Foundation works for a brighter tomorrow for those affected by MS: <http://www.msfacts.org/>.
4. Multiple Sclerosis Association of America seeks to enrich the quality of life for individuals with multiple sclerosis: <http://www.msaa.com/>.
5. MSWorld's Chat & Message Board features patients helping patients: <http://www.msworld.org/>.

Online Peer Support Groups

1. Friends with MS website: <http://friendswithms.com/forum>: <http://health.groups.yahoo.com/group/FriendsWithMS/>.
2. My MSViews: website: <http://www.mysviews.org> forum: http://health.groups.yahoo.com/group/MSViews_Multiple_Sclerosis/.
3. MS Support Group: <http://health.groups.yahoo.com/group/mscured/>.
4. The MS Carousel—A Place to Meet With People Who Understand MS! <http://health.groups.yahoo.com/group/themscarousel/>.

...Myasthenia Gravis

Websites and Chat Rooms

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

Online Peer Support Groups

1. MGFA's Forum: <http://health.groups.yahoo.com/group/MGnet/>.
2. Bette's Myasthenia Gravis Support: <http://health.groups.yahoo.com/group/bettesmyastheniagravisupport/>.
3. Maddy's MG Support: <http://health.groups.yahoo.com/group/maddysmgsupport/>.

...Myositis

Websites

1. 
THE MYOSITIS ASSOCIATION
The mission of The Myositis Association, www.myositis.org, is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases.
202-887-0088
2. International Myositis Assessment and Clinical Studies Group is a coalition of healthcare providers and researchers with global approaches to improved treatments and understanding of myositis: <https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main>.
3. The Cure JM Foundation was created specifically to find a cure for Juvenile Myositis (JM), while also providing support and information for families affected by JM. <http://curejm.com>

Wanted to Know About...

Online Peer Support Links

1. Juvenile Myositis Family Support Network:
http://www.curejm.com/family_support/index.htm
2. Myositis Association Community Forum: www.myositis.org
3. Myositis Support Group UK: <http://www.myositis.org.uk/>
4. Yahoo Myositis Support Group Discussion Board:
<http://health.groups.yahoo.com/group/OurMyositis/>

...Peripheral Neuropathy (PN)

Websites

1.

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

Support Groups

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

Online Peer Support Links

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

...Primary Immune Deficiency Disease (PID)

Websites and Chat Rooms

1.

| | |
|---|--|
|  | The Immune Deficiency Foundation (IDF), www.primaryimmune.org , is dedicated to improving the diagnosis and treatment of PID through research and education. 800-296-4433 |
|---|--|
2.

| | |
|---|--|
|  | 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 |
|---|--|
3. The National Institute of Child Health and Human Development (NICHD), www.nichd.nih.gov/, is part of the National Institutes of Health. Go to the "Health Information and Media" tab on the website and do a search under "primary immunodeficiency."
4. The American Academy of Allergy, Asthma & Immunology, www.aaaai.org, has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.

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

Online Pamphlets

1. Go to the National Institute of Allergy and Infectious Diseases site at www.niaid.nih.gov/ and search for "primary immune deficiency."
2. "Understanding the Immune System: How It Works," by the U.S. Department of Health and Human Services, is found at www.niaid.nih.gov/publications/immune/the_immune_system.pdf.
3. "NIAID Initiative Addresses Primary Immune Deficiency Diseases by National Institute of Allergy and Infectious Diseases" is located at <http://www3.niaid.nih.gov/news/newsreleases/2003/pirc.htm>.

Online Peer Support Links

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

...General Resources

Product Information

1. To learn more about Vivaglobin—the subcutaneous immune globulin (SCIG) go to: www.vivaglobin.com.
2. For more information about the 10% IVIG solution Gammagard Liquid, go to www.gammagardliquid.com.
3. Learn about IVIG treatment with Gamunex at www.gamunex.com.
4. For information about influenza and the influenza vaccine, visit www.cdc.gov/flu or call 800-CDC-INFO (800-232-4636).

Other Organizations

1. For suggestions on how to deal with the medical and emotional impact of caring for an ill child, go to www.kidshealth.org/parent/system/ill/seriously_ill.html.
2. The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at www.ncqa.org. ➤

3. The nonprofit Patient Advocate Foundation, www.patientadvocate.org, seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274

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

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

6. For a pediatrician's guide to your child's health and safety, visit www.keepkidshealthy.com.

7. The National Organization for Rare Diseases, at www.rarediseases.org, provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.

8. American Autoimmune Related Diseases Association (AARDA) www.aarda.org brings national focus to autoimmunity through research, education and patient services. 800-598-4668

9. Band-Aides and Blackboards: <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>, started by a nurse working on her dissertation, focuses on children with chronic illness.

Education and Disability Resources

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

2. Social Security: www.ssa.gov/disability/

3. California State Disability Insurance (SDI): www.edd.ca.gov (Please note that each state has a different disability program.)

4. IDEA 2004 Resources: <http://www.ed.gov/policy/speced/guid/idea/idea2004.html> News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities.

5. The National Disabilities Rights Network: www.ndrn.org. This website offers a search tool to find resources in your state to assist with school rights and advocacy.

6. U.S. Department of Education: www.ed.gov offers a Parents section that has a subsection titled "My Child's Special Needs."

7. U.S. Department of Health and Human Services, Office of Civil Rights: <http://www.hhs.gov/ocr/504.html> spells out your rights under Section 504 of the Rehabilitation Act.

8. Wrightslaw: <http://www.wrightslaw.com/>. Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities.

Books and Articles

1. "21st Century Complete Medical Guide to Primary Immune Deficiency, Severe Combined Immunodeficiency (SCID), Chronic Granulomatous Disease (CGD), for Patients and Physicians," by PM Medical Health News, contains federal government clinical data and practical information for patients and physicians.

2. "A Handbook for Care Givers," by Helen Rummelsburg, gives an account of caring for her husband and offers helpful hints for patients and caregivers. Available at the GBS website bookstore at www.gbsfi.com.

3. "Anatomy of an Illness," by Norman Cousins, is a bestseller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body's capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.

4. "A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed," by Linda Wilmschurst and Alan W. Brue, is available on Amazon.com.

5. "Bed Number Ten," by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.

6. "Caring for a Child With GBS," by Patricia Schardt, is a short guide written by a mother of a child with CIDP. Available at the GBS website bookstore at www.gbsfi.com.

7. "The Confused Consumer's Guide to Choosing a Health Care Plan: Everything You Need to Know," by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.

8. "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.

9. "The Everyday Guide to Special Education Law," by Randy Chapman, Esq., makes the law accessible to parents so they can be more effective advocates for their children. Available at <http://www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15>

10. "If You're Having a Crummy Day, Brush Off the Crumbs!," by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.

11. "Inclusion-Body Myositis and Myopathies," by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.

12. "Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration," by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.

13. "Living With Myositis," edited by Jenny Fenton, is an accessible, realistic and sympathetic guide to facts, feelings and future hopes.

14. "Managing Pain Before It Manages You," by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.

15. "Medifocus Guide to Peripheral Neuropathy," is a guide to current and relevant PN research, organized into categories for easy reading.

16. "Myositis—A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References," by ICON Health Publications, is a three-in-one reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.

17. "No Laughing Matter," by Joseph Heller (the best-selling author of Catch-22), who teamed up with Speed Vogel, his best friend, to describe Heller's battle with and triumph over GBS.

18. "Not Dead Yet: a Long Strange Trip From Doctor to Patient and Back Again," by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.

You Ever Wanted to Know continued...

19. "Numb Toes and Aching Soles," by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
20. "Numb Toes and Other Woes," by John Senneff, is the second in a series of three books. It focuses on clinical findings and treatment strategies for PN.
21. "Nutrients for Neuropathy," by John Senneff, the third in the Numb Toes series, is focused exclusively on nutrient supplementation as a means for managing PN.
22. "The Official Patient's Sourcebook on Inclusion Body Myositis," by James N. Parker (Editor) and Philip M. Parker (Editor), is a reference manual for self-directed patient research.
23. "Pride and the Daily Marathon," by Jonathan Cole, describes how Ian Waterman was suddenly struck down at work by a rare neurological illness that deprived him of all sensation below the neck, and how he reclaimed a life of full mobility.
24. "Prontoia Is the Antidote for Paranoia," by Rob Breznsy, explores the best way to attract the blessings that the world is conspiring to give us.
25. "When You're Ill or Incapacitated" comprises one-half the booklet it shares with "When You're the Caregiver," both written by James E. Miller, suggesting 12 things to remember or do in each role.

IG Manufacturer Websites

Baxter: www.baxter.com
Grifols: www.grifolsusa.com
Octapharma: www.octapharma.com
Talecris: www.talecris.com
ZLB Behring: www.zlbbehring.com

Pump and Needle Websites

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

...Nutrition and Food Safety Information

1. American Board of Physician Nutrition Specialists: <http://www.ipnec.org>
2. American Dietetic Association: <http://www.eatright.org>
3. American Gastroenterological Association: <http://www.gastro.org>
4. North American Society for Pediatric Gastroenterology Hepatology and Nutrition: <http://www.naspgn.org/>
5. Bovine spongiform encephalopathy (BSE)
http://www.aphis.usda.gov/newsroom/hot_issues/bse.shtml
6. Childhood choking prevention:
<http://www.ific.org/publications/brochures/index.cfm>
7. American Academy of Allergy, Asthma & Immunology (AAAAI): www.aaaai.org
Patient Information and Physician Referral Line: 800-822-2762
8. The Food Allergy & Anaphylaxis Network: www.foodallergy.org 800-929-4040
9. U. S. Food and Drug Administration, Center for Food Safety and Applied Nutrition www.cfsan.fda.gov Food Information Line (24 hours): 888-SAFEFOOD
10. USDA Meat and Poultry Hotline: www.IsItDoneYet.gov 888-MPHotline
888-674-6854 · TTY: 800-256-7072

...Resources Just for Kids

1. "Germs Make Me Sick," by Melvin Berger, explains with colorful illustrations how your body fights germs.

2. "Little Tree: A Story for Children With Serious Medical Illness," by Joyce C. Mills, is a comforting fable for young children facing serious life challenges.
3. "This Is My IVIG Book," written from a 3-year-old's perspective about his infusions, comes with a kit for other children to create their own personalized book. Free from Baxter at <http://www.immunedisease.com/US/>.
4. "Our Immune System," enables children who are immune deficient and their families to explore together the immune system. Available from the Immune Deficiency Foundation at www.primaryimmune.org.

...Scholarships

Immune Deficiency Foundation Scholarship

This award is available to individuals diagnosed with a primary immune deficiency disease. <http://www.primaryimmune.org/services/scholarship.htm> 800-296-4433

The ELA Scholarship

This scholarship provides financial assistance to women with physical disabilities who are enrolled in a graduate program in a college or university in the United States. <http://www.ela.org/scholarships/scholarships.html> 626-398-8840

Bank of America Abilities Scholarship Program

These scholarships are awarded to students with disabilities who have a career interest in finance, business or computer systems. http://www.scholarshipprograms.org/bada/bada_2005_ins.htm 864-268-3363

Foundation for Exceptional Children

The Stanley E. Jackson Award for Gifted/Talented Students is awarded to students with a disability. <http://yesican.cec.sped.org/scholarship/index.html> 800-224-6830

Joyce Walsh Junior Scholarship for the Handicapped

This scholarship is awarded to disabled instrumentalists or vocalist members of National Federation of Music Clubs. <http://www.mfmc.net/scholarships.html> 317-638-4003

Panasonic Young Soloists Award

This award is given to vocalists or instrumentalists under age 25 who are permanently disabled and interested in studying music. http://www.panasonic.com/corp_cont/celebrating.asp 202-628-2800

Horatio Alger Association Scholarship Program

The Horatio Alger Association provides financial assistance to students who have exhibited integrity and perseverance in overcoming personal adversity and who aspire to pursue higher education. <http://www.horatioalger.com> 703-684-9444

Central Intelligence Agency: Undergraduate Program

The CIA Summer Internship Program is open to undergraduate students, particularly minorities and people with disabilities, who have completed one or two years of college-level academic study. <http://www.cia.gov/employment/student.html> 800-368-3886

Through the Looking Glass

This nonprofit offers college scholarships for individuals with parents with disabilities. www.lookingglass.org 800-644-2666

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

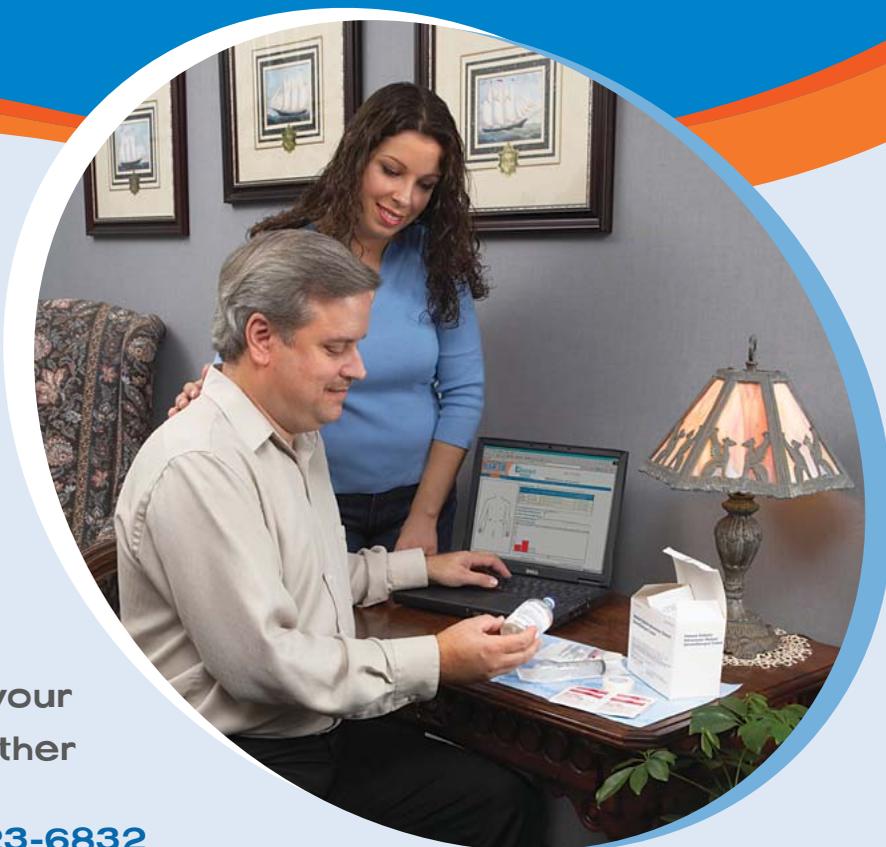
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