Properly Disposing of Unused Medicines

How expired medicines can pose a threat

Weight Management and Immune Disorders

Understanding and Coping with Neuropathy

How to Choose a Specialty Pharmacy

Infusion Environments: A Comparison
A bout IG Livin g

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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The Power of Connection

RECENTLY, I RECEIVED a phone call from a reader, John, who several years ago was interviewed for an article published in IG Living. The article was about stiff person syndrome (SPS), an autoimmune disease from which he suffers. Because SPS is so rare, John thought other readers would be interested to hear how media sources like IG Living and, more importantly, the growing number of social networking sites on the Internet can make such a difference in people’s lives — most notably for those who have a special need to connect with others like themselves.

John’s story is indeed interesting, and it all started with him and his now wife, Debbie, being featured in that article in IG Living. But, their true connection was made possible through an online support group created by Debbie who also has SPS. Read their story in our Let’s Talk interview on page 36 of this issue.

Stories like John and Debbie’s are becoming less and less unique, and finding ways to connect with others has never been easier or more important, as the number of individuals suffering from immune mediated diseases increases. According to a recent article in The Washington Post, online health sites have been booming in the past five years, “driven by the popularity of social networking and patients’ desire to become more empowered in the increasingly complex medical field.” In fact, officials of the Health 2.0 Conference, which tracks the industry, estimate that the number of these sites climbed to nearly 500 from just 35 four years ago.

While these sites originally looked more like an encyclopedic-styled WebMD, they now have become more interactive and case study-oriented. Some of the more popular sites include Inspire, PatientsLikeMe and CureTogether. Inspire, for instance, is a health-focused social networking site with 130,000 members, and it partners with 70 associations that advocate for patients with various diseases. The site features hundreds of support groups, 49 of which are for autoimmune diseases.

Earlier this year, the Immune Deficiency Foundation (IDF) created four interactive social networking portals where individuals with primary immune deficiency can connect. These include IDF Friends (my.primaryimmune.org), IDF Arcade (www.primaryimmune.org/flashgames/idf_flashgames.asp) for children ages 4 to 12, IDF Common Ground (www.idfcommonground.org) for teens and young adults and IDF Reel Stories (www.youtube.com/idfreelstories) where individuals can create and review videos that relate to life experiences with primary immunodeficiencies.

We at IG Living are no stranger to the demand for this type of online communication either. While our articles provide an initial connecting point for members of the IG Living community, we also have created an IG Living Facebook page just for our readers where you can get to know one another. We encourage you to become a fan of our Facebook site, which can be accessed at www.igliving.com. You might locate someone you met or spoke with in passing at a recent conference or through one of our monthly IG Living Readers Teleforns. Or, you never know, like John, you might even meet your future spouse. Whatever you experience, we hope you’ll let us know by posting a comment or emailing us at editor@igliving.com.

Ronale Tucker Rhodes, MS, Editor

Note: Be sure to reference our Resources section in the back of each issue of IG Living, which lists online peer support groups for various disease states.
“Unneeded and expired medicines in people’s homes may not seem like a problem to many, but they pose a great risk.”

“Meaningful outcome measures and effective therapeutic exercise remain important in the medical management of the disease.”

“People with autoimmune disorders are more prone to peripheral neuropathy, which occurs when tissue in the peripheral nervous system comes under attack.”

“Choosing a specialty pharmacy and/or homecare provider entails weighing all of the issues that should be considered when choosing any other business service.”

“Choosing one or more of these products, patients should consider their needs, function, ability and size.”

“In addition to the growth experience of being away from mom and dad for a week, and the relief of making new friends who are different the same way you are, many children learn important life skills at camps for special-needs children.”

“For those who already have decreased mobility because of neuropathy, multiple sclerosis or other debilitating disease, even a few extra pounds can feel like a ton, making normal daily activities more difficult.”

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

- Email IG Living to be added to our email invitation list for the telefours.
- IG Living will send you invitations to let you know when the two-per-month, hosted, toll-free telefours will be held, as well as what topic relevant to the IG community will be discussed.
- The moderated, hour-long calls will be filled on a first-come, first-served basis and will be limited to 15 readers.

In addition to connecting with others, IG Living’s patient advocate can help you determine if there’s a patient organization support group in your area. Or, she can help you to start an IGL Readers Group of your own. To join a group or start one in your area, visit www.IGLiving.com and click on IGL Readers Groups.

Sign up for the Telefours now by emailing kmcfalls@IGLiving.com or calling (888) 433-3888, ext. 1349.
Clarifying the Source of Source Plasma

I wanted to point out an error in the article titled “Plasma Derivatives: An Overview” by Catherine Billey [June-July 2009, p.12]. The article provides a definition of source plasma that states, “Source plasma comes from voluntary whole blood donations.” In fact, source plasma in the United States primarily comes from paid donations and is by definition collected via plasmapheresis. Some of the plasma that is used for fractionation does come from voluntary whole blood donations, but this is called recovered plasma. Recovered plasma is collected at community blood centers and is not collected at plasma donation centers. In 2007, about 17 percent of the plasma available for fractionation that was collected in the U.S. was recovered plasma.

— Jennifer Ficenec
Director, Business Development
Group Services for America’s Blood Centers

The Editor replies:

Thank you for pointing out that error. To add to your point, our readers should know that the amount of blood collected by plasmapheresis in commercial plasma industry facilities is roughly 11 million liters from more than 15 million paid donations in the U.S. The remaining liters are recovered from whole blood donations at community or American Red Cross (ARC) blood banks around the world.

GI Distress

In the June-July issue of IG Living, Kris [McFalls, IG Living’s patient advocate] talked about digestive system disorders in relation to the immune-deficient population. Dr. Harville, in his response, did a nice job of describing how this could occur, but I thought perhaps a more specific look at some of the diseases would be in order.

I was diagnosed in 1968 by a gastroenterologist whom I had gone to for gastrointestinal (GI) problems with nodular lymphoid hyperplasia and disagammaglobulinemia. They did nothing [for] treatment except to follow me with an upper and lower GI series, because they thought it was a precancerous condition. It was not until 1990 that an oncologist in a hospital where I was being treated for pneumonia diagnosed me with CVID. [After that, I was] seen for GI problems, even as IVIG was started and continued for 13 years. Only then, through the Immune Deficiency Foundation, did I find … an immunologist in my area [who changed] my brand of [IG] product, my amount of IVIG and my interval between infusions to bring me to a healthy enough condition to continue working.

My point is that this disease [may] be manifesting itself in other patients with primary immune deficiency disease (PIDD). I have a massive series of growths in the colon that produce some distress, cramping, gas and loose bowel movements. I am currently followed with a colonoscopy and an endoscopic exam every two years, but the IVIG seems to have made some of the growths disappear and the manifestations of disagreeable symptoms less, and they have no idea why.

Patients with PIDD should be aware that such things can and do occur, and they might wish to be followed by a GI doctor, as well as the others that they currently see.

— Frank Meuers
Minnesota

Patient Advocate Supports Readers

I am 29 years old, and I have been diagnosed with autoimmune diseases for over seven years now, and have been a sick person since childhood. I was originally diagnosed with lupus (SLE) and vasculitis, as well as many other diseases, but these are the main ones. After my recent hospital stay of 18 days, I saw a new neurologist who diagnosed me with postural orthostatic tachycardia syndrome (POTS) and dermatomyositis. I still have the vasculitis, which is controlled to my hands, but lupus is still up in the air. I am so weak, and my blood pressure and pulse are so out of control, that I’m ready for the IVIG to see if it will help…. I appreciate your magazine and Kris McFalls [IG Living’s patient advocate]. Kris really knows what she is talking about and sure is there to help and support in any way. God bless her and your IG Living staff for making it known to the community that there are others out there like us.

— Reader
Katy, Texas
Insurance

Medicare Part D Drug Plan Premiums Rise

Monthly premiums for Medicare beneficiaries who are enrolled in Part D stand-alone prescription drug plans will rise 11 percent on average to $38.85 in 2010 if beneficiaries stay in their current plans, according to a new Kaiser Family Foundation analysis. Average monthly premiums have gone up by 50 percent for stand-alone Part D prescription drug plans since the launch of Medicare’s drug benefit in 2006, when monthly premiums averaged $25.93.

As many as 1.2 million people on Medicare will see monthly premiums increase by at least $10 unless they switch to a less-expensive plan. Many of these individuals will also receive lower Social Security checks because their Part D premiums are deducted directly from their payments, and there will be no cost-of-living increase for Social Security in 2010. In addition, for the first time since the Medicare drug benefit launched, a majority of stand-alone drug plans (61 percent) will require enrollees to meet a deductible before coverage begins, up from 45 percent last year and 42 percent in 2006.

The vast majority (80 percent) of all stand-alone Part D plans will have a gap in coverage, known as the “doughnut hole,” up from 75 percent last year. When enrollees reach the gap, they will have to pay the full price of their medications. And, coverage will be limited to generic drugs for the 20 percent of stand-alone plans with some coverage in the gap. Although members of Congress proposed different options to remove the doughnut hole and decrease premiums, none of the health insurance reform proposals do either. However, options do exist to decrease the coverage gap (doughnut hole).

Changes in Medicare Part D and other healthcare plans also shift some coverages to Tier IV and V drug benefit plans. These coverages include plasma therapies, biologics and other expensive therapies that will no longer be covered under major medical or Tier I, II and III drug plans in which patients are responsible to pay a standard copay. Instead, patients now may be forced to pay coinsurance, which is 10 percent to 30 percent of the cost of the drug.

Research

Low IgG Levels Lead to Severe Flu

Australian researchers specializing in infectious diseases found that pregnant women who became severely ill with the H1N1 flu had low levels of IgG, which helps to fight off the virus and help the body respond to vaccine. On the other hand, moderately ill pregnant women were much less likely to have significantly suppressed levels of the antibody.

The researchers tested patients for antibody levels and found that patients who needed intensive care were IgG2-deficient. Severe cases had IgG2 levels that were about one-third of those detected in people who were moderately ill. Three of four critically ill patients treated with immune globulin survived. While the testing was performed only in pregnant women, the scientists believe that the deficiency might explain why a small subset of swine flu cases become gravely ill, while most people suffer only through a bout of the flu. The study was conducted at Austin Health, a network of three hospitals in Melbourne. However, because the testing involved a small number of people, further study is needed.
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“Managed care organizations are looking to restrict patient access to physician-administered biologics because these agents are harder to control in terms of cost outlays — in part due to physicians preferentially prescribing agents such as Remicade so the physician can purchase the agent at a discount relative to the reimbursement rate and thus maintain a profit margin on the procedure,” said Michael Malecki, PhD, product manager for Formulary Forum. “Maintaining control of the supply chain will be critical to the future profitability of managed care organizations, and plans are aware of this fact. By 2014, for example, 84 percent of surveyed pharmacy directors say their organization will mandate IV biologics be purchased from an authorized vendor (e.g., specialty pharmacy).”

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Scientists Find Way to Rebuild Immunity

A critical advance in regenerative medicine makes possible new approaches to treating people with severe immune deficiencies, such as children born with little or no immune system or people who have had chemotherapy. Scientists at Sunnybrook Research Institute, Toronto, Ont., created human progenitor T cells from stem cells in the lab using a method that they patented, according to the study, which was published in the July 30 edition of Blood. Subsequently, the scientists implanted the progenitor T cells into immune-deficient mice, in which the cells traveled to the thymus and produced mature T cells. T cells are white blood cells that normally develop in the thymus after relocating there from bone marrow, and are essential to the body’s ability to fight off disease, bacteria or infection.

“What’s exciting about it is that the same progenitor cell we’re making in vitro is a very rare cell in the actual organ [thymus]; and, as we age, there are fewer of them and they’re less effective,” said lead researcher Dr. Juan Carlos Zuniga-Pflucker. “So, if we increase their numbers, we have a way to increase the flow of development of T cells in the organ. Generation of more T cells means a healthier immune system.” While still experimental, the findings have potential clinical relevance to provide a new mechanism to treat immune diseases, and also suggest routes for the design of better cell-based therapies.

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HAE is a genetic disorder that affects between 6,000 and 10,000 people in the U.S., and is caused by a deficiency of C1-INH. It is inherited in an autosomal dominant manner. Symptoms of HAE include episodes of edema or swelling in the face and the abdomen. Berinert is distributed by FFF Enterprises, Inc.
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In the study reported on in the November edition of *The Lancet*, researchers enrolled 1,006 women under 50 years of age, and used questionnaires to measure the prevalence of various risk factors, with blood samples taken to measure phospholipid antibodies, including LA. The group of patients included 175 women who had a stroke, 203 who had a heart attack and 628 healthy controls. The researchers found that four of 628 healthy controls had LA and estimated the prevalence in women in the general population to be seven in 1,000. LA increased the risk of stroke 43-fold compared with healthy controls. For those women with LA who smoke, the risk was raised 87-fold, and for those with LA who use oral contraceptives, the risk was increased more than 200-fold.

The researchers concluded that screening for LA in young women with ischemic stroke seems warranted, and young women with LA should be warned about the dangers of smoking and using oral contraceptives.

Did You Know?

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RTL1000 is being developed as a drug to stop immune system T cells from attacking healthy cells. When immune system T cells receive a faulty message to attack important parts of the body, the drug mimics the messenger molecule to deliver a new command to T cells: Call off the attack.

Artielle hopes to be able to customize the basic drug platform to fight multiple diseases of the immune system, including celiac disease, rheumatoid arthritis and type 1 diabetes. The company will submit its findings to the U.S. Food and Drug Administration for review, and hopes to begin a second stage of clinical trials in 2010.

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Did You Know?

An initial analysis of 1,400 adults hospitalized for H1N1 found that 26 percent had asthma. An article in The Journal of Allergy and Clinical Immunology recommends that people with asthma who have suspected or confirmed influenza should be vaccinated with the seasonal and H1N1 vaccines, and should be strongly considered for antiviral medications.

— Centers for Disease Control and Prevention
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Research

Osteoporosis and Celiac Disease Link

A link between osteoporosis and celiac disease — the first case in which an autoimmune response has been found to directly damage bones — has been found by researchers at the University of Edinburgh. The scientists studied a protein called osteoprotegerin, which in healthy people is critical in maintaining bone health by controlling the rate at which bone tissue is removed. Twenty percent of people who have celiac disease produce antibodies that attack osteoprotegerin, resulting in rapid destruction of the bone and the development of osteoporosis.

It was originally believed that the reason individuals with celiac often develop osteoporosis was due to their inability to properly absorb calcium and vitamin D. But, this new finding showed that the form of osteoporosis found in patients with celiac does not respond to supplementation with calcium and vitamin D, yet it can be treated with drugs that prevent bone loss, such as bisphosphonates.

People and Places in the News

Dr. Jordan S. Orange, a pediatric immunologist at The Children’s Hospital of Philadelphia, received the prestigious American Philosophical Society’s Judson Daland Prize for his contributions to research and treatment of inherited immune deficiency diseases. The annual award for clinical investigation recognizes outstanding achievements in patient-oriented research. Honorees are nominated by chairs of clinical departments at U.S. medical schools or hospitals and selected by a distinguished committee of biomedical researchers. Dr. Orange’s work involves the innate immune system, the body’s first defense against life-threatening infections and diseases. His particular research focus is natural killer cells, a major component of the innate immune system, which have an inherent ability to destroy cancer or virus-infected cells.

In October, Grifols broke ground on a 72,000-square-foot plasma research and testing facility in San Marcos, Calif., which is expected to open in approximately one year. The facility will test and process human blood plasma, from which the company will provide the initial components of products for use in the treatment of shock, trauma and burns, primary immune deficiency diseases and bleed disorders such as hemophilia and Von Willebrand disease. The $76 million investment in the facility is expected to bring 190 jobs to the city.

The University of California, San Francisco, is leading a new research consortium to study severe and often life-threatening pediatric immune disorders and how to improve treatment for them. Using an initial $6.25 million in National Institutes of Health funding, the UCSF-led Primary Immune Deficiency Consortium includes 13 research centers throughout the nation. Morton Cowan, MD, chief of the pediatric blood and marrow transplant program at UCSF Children’s Hospital, will serve as the consortium’s principal investigator.

The HelpCureChildhoodDiabetes.org website was built and launched by parents of children with type 1 diabetes. The goal of the website is to help fund the research of Dr. Denise Faustman, a scientist who is making progress in understanding and finding a cure for the autoimmune disease of diabetes. Dr. Faustman’s research also offers hope for a cure for other autoimmune diseases, such as muscular sclerosis and rheumatoid arthritis.

The Kaiser Family Foundation’s Commission on Medicaid and the Uninsured has updated its online database of Medicaid benefits (medicaidbenefits.kff.org) to include data from October 2008, the most recent available. The comprehensive database houses information on Medicaid acute and long-term care benefits in the 50 states, the District of Columbia and the U.S. territories. Included are data about 46 services, including whether the benefit is covered, the populations that are eli-
Research

Drug Patches May Cause Burns During MRIs

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Dr. Sandra Kweder, the FDA’s deputy drug director, estimates that more than a quarter of the 60 different drug patches sold contain traces of aluminum or other metals in their backing, the part that makes them stick to the skin. The affected patches, which may appear to be clear, contain just enough metal to conduct electricity, and during an MRI scan can overheat and cause a skin burn similar to a bad sunburn.

After learning of a few patients who suffered patch burns, although none severe, the FDA tracked the source of one burn to Teva Pharmaceuticals’ fentanyl painkiller patch, which lacked the MRI warning. The FDA then found that a variety of other drug patches also lacked the warning.

The FDA has issued a public health advisory, asking patients to tell their doctors about any medication patches so the professional can decide which should be removed before an MRI, how soon before the scan, and when it can be reapplied. “If there’s any uncertainty, just don’t wear it in the machine,” Kweder said. “It’s just the smart thing to do.”

New Drug to Treat Lupus

The first new treatment in more than 40 years for the chronic autoimmune disease lupus could soon be available following positive results from a Phase III clinical trial. Human Genome Sciences and its partner GlaxoSmithKline will file for approval with the U.S. Food and Drug Administration, as well as drug agencies in Europe, during the first half of 2010 after achieving a second successful trial with the drug Benlysta (belimumab).
**Research**

**Osteoporosis and Celiac Disease Link**

A link between osteoporosis and celiac disease — the first case in which an autoimmune response has been found to directly damage bones — has been found by researchers at the University of Edinburgh. The scientists studied a protein called osteoprotegerin, which in healthy people is critical in maintaining bone health by controlling the rate at which bone tissue is removed. Twenty percent of people who have celiac disease produce antibodies that attack osteoprotegerin, resulting in rapid destruction of the bone and the development of osteoporosis.

It was originally believed that the reason individuals with celiac often develop osteoporosis was due to their inability to properly absorb calcium and vitamin D. But, this new finding showed that the form of osteoporosis found in patients with celiac does not respond to supplementation with calcium and vitamin D, yet it can be treated with drugs that prevent bone loss, such as bisphosphonates.

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**People and Places in the News**

Dr. Jordan S. Orange, a pediatric immunologist at The Children’s Hospital of Philadelphia, received the prestigious American Philosophical Society’s Judson Daland Prize for his contributions to research and treatment of inherited immune deficiency diseases. The annual award for clinical investigation recognizes outstanding achievements in patient-oriented research. Honorees are nominated by chairs of clinical departments at U.S. medical schools or hospitals and selected by a distinguished committee of biomedical researchers. Dr. Orange’s work involves the innate immune system, the body’s first defense against life-threatening infections and diseases. His particular research focus is natural killer cells, a major component of the innate immune system, which have an inherent ability to destroy cancer or virus-infected cells.

In October, Grifols broke ground on a 72,000-square-foot plasma research and testing facility in San Marcos, Calif., which is expected to open in approximately one year. The facility will test and process human blood plasma, from which the company will provide the initial components of products for use in the treatment of shock, trauma and burns, primary immune deficiency diseases and bleed disorders such as hemophilia and Von Willebrand disease. The $76 million investment in the facility is expected to bring 190 jobs to the city.

The University of California, San Francisco, is leading a new research consortium to study severe and often life-threatening pediatric immune disorders and how to improve treatment for them. Using an initial $6.25 million in National Institutes of Health funding, the UCSF-led Primary Immune Deficiency Consortium includes 13 research centers throughout the nation. Morton Cowan, MD, chief of the pediatric blood and marrow transplant program at UCSF Children’s Hospital, will serve as the consortium’s principal investigator.

The HelpCureChildhoodDiabetes.org website was built and launched by parents of children with type 1 diabetes. The goal of the website is to help fund the research of Dr. Denise Faustman, a scientist who is making progress in understanding and finding a cure for the autoimmune disease of diabetes. Dr. Faustman’s research also offers hope for a cure for other autoimmune diseases, such as muscular sclerosis and rheumatoid arthritis.

The Kaiser Family Foundation’s Commission on Medicaid and the Uninsured has updated its online database of Medicaid benefits (medicaidbenefits.kff.org) to include data from October 2008, the most recent available. The comprehensive database houses information on Medicaid acute and long-term care benefits in the 50 states, the District of Columbia and the U.S. territories. Included are data about 46 services, including whether the benefit is covered, the populations that are eli-
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Most immune globulin (IG) patients have a choice of infusion environments. And, the decision to infuse in a hospital, infusion clinic or at home is driven by a variety of reasons. But the chief considerations include cost, safety and privacy. In addition, patient age can be a factor; the choice made for a child or young adult may not be right for an older adult, and vice versa.

Costs
Costs related to the site of care include doctor visits, facility charges, administration fees, supplies, labs and nursing. In general, the costs of infusion in a hospital are highest, followed by slightly lower costs in an infusion clinic and even lower costs at home. In addition, whether the infusions are intravenous (IV) or subcutaneous (SC) influences cost. During IVIG infusions, medical supervision is required, whereas SCIG patients who self-infuse incur no infusion nursing costs. Yet, even for IVIG patients, the cost to infuse at home is less than at a healthcare site.

One of the cost considerations for IVIG patients who prefer home treatment (mostly because it reduces the expense and time of traveling to a clinical setting) is that Medicare Part B will pay only for IVIG preparation in the home for primary immune deficiency (PIDD) patients. Unless these patients are certified as homebound, nursing and supplies in the home are not covered. For indications other than PIDD, IVIG in the home can be covered under Medicare Part D, but again, supplies and nursing are not covered. Since Medicare Part D reimbursement is typically higher, some homecare companies will often bundle the cost of nursing with the cost of the IVIG product if the reimbursement rate is high enough. In addition, many HMOs don’t allow for IVIG home therapy because they are not set up to accommodate it.

Overall, SCIG therapy in the home setting has a more favorable reimbursement rate than IVIG therapy. And, Medicare covers SCIG under the durable medical equipment (DME) benefit because, under the FDA approval, SCIG requires the use of a mechanical pump.

Safety
Protocol requires that patients receive at least their first infusion in a clinical setting, whether infusing subcutaneously or intravenously. However, because IVIG requires monitoring by either an infusion nurse or doctor, choices may be limited for some. Many IVIG patients can be infused safely at home, while others and their doctors may prefer the higher level of safety in a hospital or clinical setting — especially for patients at high risk of anaphylactic reaction or other issues such as myocardial infarction, brittle asthma, renal disease, etc., says Dr. Terry Harville, medical director at the Special Immunology Laboratory at the University of Arkansas for Medical Sciences.

For instance, IVIG patients have a higher risk of thrombosis because infusion is administered through the vein. This risk is further heightened by a health history of diabetes, renal dysfunction, age (65 and older), coronary artery disease, hypertension, cerebrovascular disease, hyperviscosity disorder (including multiple myeloma, macroglobulinemia and polycythemia), thrombotic events and peripheral vascular disease. In addition, any patient who has had a vascular or cardiac episode while receiving IVG should be infused in a monitored setting.

For some patients, medical status will play a role in the site of care decision. For example, some patients have autoimmune conditions that require...
higher IVIG dosings that may be difficult to be delivered subcutaneously, thus necessitating IVIG in a clinical setting. Other patients may be more likely to be noncompliant with therapy. In these instances, clinical infusions allow doctors and/or nurses to interact with patients on a frequent basis and provide a higher level of supervision for monitoring patients’ overall health and response to treatment. This higher level of supervision can protect against desensitization, a lack of awareness many patients can develop when they are so adept at living with chronic disease that they become anesthetized to symptoms that may be precursors of an increased disease state or of oncoming infection. Desensitization causes patients to sometimes fail to be good historians of their disease process, which can lead to less-than-optimal treatment. However, experienced infusion nurses who have monthly contact with patients can quickly spot subtle changes in patients’ health. In fact, these nurses become skilled at asking questions that help the patients become better historians of their health status.

Regardless of whether patients are being treated with IVIG or SCIG, the risk of contaminated products is the same. All IG products must meet certain criteria established by the FDA for purity and safety. Yet, because IG is derived from human plasma, risk of potentially infectious agents cannot be totally eliminated. In the U.S., however, there has never been a documented case of HIV transmitted in IG.

The final safety consideration centers on exposure to infection. Theoretically, there is a higher risk of contracting infection in a hospital or infusion clinic through exposure to other patients who may be sick.

Privacy
Privacy is often an important concern for patients. In a hospital or infusion clinic, visual privacy may be available, but rarely auditory privacy. Typically, infusion clinics consist of one large room, with multiple chairs for patients, screened by curtains. With no solid room dividers, complete privacy is not possible. In contrast, infusing in the privacy of a home offers convenience, autonomy and flexibility not found in the clinical setting.

Many patients can be infused safely at home, while others and their doctors may prefer the higher level of safety in a hospital or clinical setting.

But privacy is not a concern for some. Many patients appreciate being with other patients going through the same treatment. In fact, they prefer the social opportunity provided at hospitals and clinics.

Patient Age
While home infusion offers many advantages to patients, there are reasons why it may not be the best treatment or the treatment of choice for children and young adults. Lack of compliance and insecurity about performing treatments are perhaps the biggest drawbacks when it comes to SCIG. Self-infusing can be scary and difficult, especially for young people. When short on confidence, they simply fail to infuse when needed — often without parents’ or medical providers’ knowledge. Providing adequate supervision during the transition to self-treatment is key to keeping young patients confident and compliant with their therapy.

A Personal Choice
In the end, the site of care is a personal decision. Home infusions may offer many cost and privacy advantages, but there are those who prefer to keep their home a home — without the medical equipment as constant reminders of their disease. In addition, many patients also prefer letting someone else take care of them for a while and appreciate the comfort and safety they experience in a clinical setting.

Each patient’s situation is unique, including medical history, response to treatment, compliance with therapy and lifestyle. All factors should be weighed to make the decision that best suits the individual needs of the patient.

Kris McFalls is the full-time patient advocate for IG Living magazine, written for patients who depend upon immune globulin products and their healthcare providers, and Ronale Tucker Rhodes, MS, is the editor of IG Living magazine.

References
How to Choose a Specialty Pharmacy and/or Homecare Company

By Kris McFalls

WHEN SELECTING a specialty pharmacy or homecare company, it is most often patients’ insurance companies or, in rare instances, the patients themselves who choose; doctors merely honor the request. In fact, many doctors and patients don’t even realize they have a choice, and they often don’t shop around or ask pointed questions until after a problem arises.

Why is this? Traditionally, decisions made about healthcare have not been treated as business transactions. While most buying decisions are made based on the best quality for the lowest cost, price isn’t even revealed in medically related transactions until the service has been rendered and the product has been dispensed. With spiraling costs, decreasing services and renewed focus on healthcare reform, the time has never been more important for patients with a chronic disease to get involved with the business transactions of the healthcare industry.

Dispensing Specialty Drugs

For most medications, doctors write prescriptions and patients take them to their local pharmacy for dispensing. This is not the case with immune globulin (IG) because it is considered a specialty drug. In short, if a drug is expensive, injectable or infusible, it is classified as a specialty drug and is dispensed by a specialty pharmacy.

Homecare companies provide the nursing services for specialty drugs, sending infusion nurses to homes to administer IG. In some instances, specialty pharmacies provide homecare services — and some homecare companies may also have specialty pharmacies.

The Role of Reimbursement

When choosing a specialty pharmacy and/or homecare provider, doctors and patients should know what their options are and how much they cost. Specifically, the following questions should be asked:

- Is the provider in the insurance company network of providers? To be sure, don’t be afraid to ask for the provider’s tax identification number, which an insurance company customer service representative can use to confirm provider status.

- What expenses are the responsibility of the insurance company, and what are the patient’s out-of-pocket expenses? Providers should give dollar amounts, in addition to percentages. When outlining benefits, a provider should also be able to discuss a patient’s lifetime cap, including the amount of the cap and how much of that cap the patient has used up to that point. Most insurance companies have a lifetime cap, or the maximum dollar amount the company will pay for healthcare costs. When patients’ covered expenses reach that cap, 100 percent of additional costs are then their responsibility. Therefore, patients should treat that cap as if it were their life savings, because it is.

- What is the out-of-pocket maximum or catastrophic level? With the exception of Medicare Part D, once patients have reached their out-of-pocket maximum, most in-network services should be 100 percent covered. Even at the catastrophic level, Medicare Part D covers only 95 percent.

- Is IG covered under major medical or the prescription plan? In some cases, if IG is covered under the prescription plan, its cost does not count against the patient’s lifetime cap.

- Is the price all-inclusive or are there added fees? Ask about administration fees, facility use fees, nursing, supplies and shipping.

- When does the provider require the patient’s portion of the payment?

- If there is a problem with the patient’s insurance, will the provider help with an appeal, or is that left up to the patient and to the doctor?

All answers to these questions should be in writing before patients agree to the service. And, patients should obtain a written copy of the insurance authorization. They should not rely on a verbal agreement of any kind. If ever there is a dispute, it is still the patient’s responsibility to pay, regardless of where the fault lies.
The Role of Nursing

A nurse’s experience and ability to train patients is the key to successful and safe treatment. Patients should treat their conversations with potential providers the way an employer would interview a prospective employee. Because most nurses can say they have experience infusing IG, patients should inquire about their the level of experience by asking how many patients they have treated and trained. Other questions to ask include:

• Does the provider have staff nurses? Keep in mind that many providers contract with nurses even if they say they don’t. To delve further, patients may want to ask if the nurse is on staff, per diem (a term commonly used by medical providers) or contracted. Companies that contract with nurses may also use the term “coordinated nursing.” This is not to say that contract nursing is necessarily a negative. On the contrary, some nursing agencies have nurses dedicated to infusion patients. No matter what the arrangement, patients should make sure that if nursing comes from a different company, that the agency is in network and follows the reimbursement guidelines and answers questions listed in the reimbursement section of this article.

• If the nurse is contracted, who carries the malpractice and liability insurance for the nurse?
• What does the provider do to ensure the nurse coming to the patient’s house is properly trained? Does the provider send a video and/or written instructions, or personally communicate with the nurse?
• Has the nurse participated in educational in-services specifically for IG?
• If the patient is a child, does the nurse have pediatric infusion experience?

Treating patients with a chronic disease requires a different skill set than treating an acute illness. For IG patients, who likely will spend more time with their nurse than their doctor, the key to good treatment relies heavily on the nurse’s skills and ability to effectively interact with patients.

The Role of Customer Service

The term “customer satisfaction” is used to assess how goods and services supplied by a company meet or surpass customers’ expectations. “In today’s world, it is especially easy for providers to justify cuts in services provided to patients due to fiscal constraints caused by margin compression and lack of payment,” says Jerome Vangheluwe, senior vice president of NuFACTOR, a specialty pharmacy of FFF Enterprises, Inc., Temecula, Calif. “All too often, many providers are forced to decide between outstanding customer service at a higher non-reimbursable cost and their own need to make enough money to survive. In reality, this puts consumers in a luck-of-the-draw situation.”

Vangheluwe explains that while the goal of most providers is to provide 100 percent patient satisfaction, sometimes factors that are out of any provider’s control prevent them from doing so. He suggests that patients shop around for a provider before settling on one. They should ask if the provider is accredited by the Joint Commission on Accreditation of Healthcare Organizations. Providers should be willing to share their philosophy on customer satisfaction, and they should have policies in place to back them up. They also should have a conflict-resolution policy, and a manager should be at patients’ disposal should they have questions or concerns. Patients, along with their physicians and insurance companies, can create the best possible outcome if they do their homework.

Patients with a chronic disease can find a provider that will make their care as worry-free as possible by asking the following questions:

• Is the provider accredited?
• Does the company provide a care plan and/or course of treatment?
• Does the provider offer disease-management tools?
• Is there 24-hour access to a pharmacist and/or nurse?
• Does the provider have an experienced patient advocate or peer contact on staff?
• What kind of durable medical equipment, such as pumps, are used? If different from your preference, would they support your choice?
• How are supplies shipped to your home?

Making an Educated Choice

Choosing a provider of infusion services requires the same diligence as any other business transaction. Essentially, patients should question the employer for whom the providers work to determine if it’s a good match for them. By doing some basic research upfront, patients can be confident that the provider they hire will put their health first.

KRIS MCFALLS is the full-time patient advocate for IG Living magazine, written for patients who depend upon immune globulin products and their healthcare providers.

DidYouKnow

Many doctors and patients don’t even realize they may actually have a choice.
Does your medicine cabinet contain so many prescription bottles that you don’t know which is the right medicine? Or, do you have a shelf (or drawer) for medicines you take every day, one for medicines you take sometimes and yet another for those you took a while ago? This may sound familiar to individuals with immune deficiency and autoimmune diseases.

Expired medicines can pose a threat to individuals and the environment if proper guidelines are not followed to dispose of them safely.

By Sarah Dewey
Currently, 91 percent of seniors and 61 percent of non-elderly adults rely on a prescription medicine on a regular basis. The average American received more than 11 prescriptions in 2006, adding up to 3.3 billion prescriptions in the United States for one year. And these numbers don’t include all the prescription and nonprescription drugs that are stockpiled in home cabinets — medicines that are expired or that are no longer needed for a variety of reasons.

Unneeded and expired medicines in homes may not seem like a problem to many, but they pose a great risk. For starters, they can be accessed by individuals to whom they can cause harm, such as children and grandchildren. Accidental pharmaceutical ingestion is the most common poison exposure category. In 2006, Poison Control Centers reported about two million cases of unintentional poisonings or poison exposures, and the Centers for Disease Control and Prevention reported that pharmaceuticals caused 95 percent of the unintentional and undetermined poisoning deaths.

Intentional misuse of pharmaceuticals stored in homes must also be considered. A study by the National Center on Addiction and Substance Abuse found that between 1992 and 2003, the number of Americans who abused pharmaceuticals had nearly doubled from 7.8 million to 15.1 million. In addition, prescription drug abuse among teens more than tripled during this time. Much of this abuse appears to be the result of easy access to prescription drugs — as easy as a loved one’s medicine cabinet.

The question is: What are people supposed to do with all these unwanted medications?

Only Rain in the Drain

In the past, people have been directed to throw unwanted and expired medications down the toilet. This is not recommended! Medication that is flushed often travels from the toilet to a wastewater treatment plant where it is mixed with bacteria. The bacteria’s job is to eat solid waste and break it down so that the water is clean enough to enter into a flowing stream or river. Because the wastewater is not treated for any chemicals or medicines, flushed antibiotics can kill the beneficial bacteria that are “on the job.”

Medicines that are flushed down toilets that are connected to a septic system go directly to wastewater and groundwater. After flushing, the solids go to a holding tank, where they are food for bacteria, and the liquids are sent into a drain field, a buried area in the yard that soaks up the liquids. Any chemical that is dissolved in the liquid in the drain field leaches into the groundwater.

Since 2007, more than 100 individual pharmaceutical medications, including antibiotics and steroids, have been identified from environmental samples and drinking water taken from locations throughout the United States. Many of these are chemicals of environmental concern, especially to aquatic animals, since they are constantly bathed in a diluted solution of whatever mixture we all

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Do-It-Yourself Disposal of Medicine

1. Remove medicine from prescription container.
2. Obscure or remove any medical and personal identifying information on the prescription container. If possible, recycle the container or include with the trash.
3. Mix medicine with unreactive material, such as dry coffee grounds or cat box filler. For best results, break up pills or capsules before mixing.*
4. Place mixture into a sealable container, such as an empty margarine container or plastic bag.
5. Put mixture in container or bag in with the trash.

* Note: Some websites that are not authorized by the United States Environmental Protection Agency recommend mixing dry pills with liquid medicine and water until the pills have dissolved, and then adding coffee grounds or cat box filler. Adding some liquid to the crushed pills is all right, but only an amount that the solid can absorb, thereby leaving the material dry. Liquids should never go to the landfill! Once at the landfill, liquids can interact with other materials, possibly dissolving some unwanted chemicals, and then leaching down to the bottom of the landfill. There, the liquid meets the landfill liner. If the liner is intact, liquids are collected and sent to the wastewater treatment center, which is exactly where pharmaceuticals do not belong. Or, if the liner is broken, the liquids will enter into the groundwater — possibly becoming someone’s drinking water.
flush down the drain! Some medication ingredients are known to affect animal reproduction, development and immune systems, as well as contribute to the evolution of antibiotic-resistant bacteria.

**Disposal Solutions**

So, if prescription medicines can’t be flushed (unless the medicine bottle instructions specifically say to do so), how can they be disposed of? Estimating more accurately how much medicine is needed when filling prescriptions is the best way to avoid having leftovers. Sample medicines or new prescriptions could be started in smaller amounts, with refills as needed. Antibiotics should be taken until the medicine is finished, unless there are complications. And, while those with chronic illnesses often get more of a medicine than is really needed for those “just-in-case” situations, this should be done only if absolutely necessary.

For expired and unwanted prescription medicines, the best disposal method is to take them to pharmaceutical take-back programs, which are typically sponsored by the clean water or hazardous waste departments in each state, county or municipality. These programs may be part of a one-time event or a permanent collection site, and they can be found by asking local solid waste departments or by checking online at [www.epa.gov/epawaste/wyl/stateprograms.htm](http://www.epa.gov/epawaste/wyl/stateprograms.htm). In addition, the Earth 911 website ([earth911.com/hazardous/medications](http://earth911.com/hazardous/medications)) lists medication recycling programs for each state.

For expired and unwanted prescriptions, the best disposal method is to take them to pharmaceutical take-back programs.

All medications gathered by these programs are treated as hazardous waste. While households are exempt from hazardous waste regulations, some products contain ingredients with hazardous properties, which are defined as flammable, corrosive, reactive and toxic. Prescription medicines can be hazardous due to their toxicity to people and the environment. Medications that are collected from take-back programs are often taken to a hazardous waste incinerator, where they are burned at high heat so that the chemical bonds are broken or the chemical structures become smaller, or where they are reduced to their elemental state (such as carbon, oxygen and hydrogen).

Many communities and states are collecting and removing pharmaceuticals. Here is a sampling of pharmaceutical take-back programs.

- **Maine** has the first statewide pharmaceutical collection program. Maine citizens obtain an envelope from local pharmacies, medical facilities and community agencies for their unwanted pharmaceuticals. They then return the envelope, confidentially and free of charge, to the Maine Drug Enforcement Agency. The state’s pilot program collected 1,000 pounds of medicines from 2,000 participants.
- **Washington** state citizens left their unwanted pharmaceuticals inside a sealed-box structure that was located inside a pharmacy and constantly monitored to prevent break-ins. Over 13 months, 6,000 pounds of pharmaceuticals were collected.
- In two years, the San Mateo County (Calif.) Police Chiefs and Sheriffs Association managed 13 drop-off sites inside their offices, where they collected more than 9,190 pounds of unused medications. For their innovative program, they received the California Governor’s Environment and Economic Leadership Award.
- A recent take-back program in San Francisco found the average household had 2.7 pounds of unwanted or expired drugs.
The third option is to “do it yourself.” In February 2007, the White House Office of National Drug Control Policy issued the first consumer guide for the proper disposal of prescription drugs, titled *How to Dispose of Unused Medicines*. The guide’s main goal is to urge people to separate medicines from the prescription bottle so that scavengers looking through trash cans can’t pull out intact and identified pills. Another goal is to show people how to make medicines unconsumable by others by mixing them with cat box litter or dry coffee grounds. (See the Do-It-Yourself sidebar on page 21.) These mixtures will likely go to sanitary landfills, depending on an area’s waste removal program. At sanitary landfills, trash is covered with soil at the end of the day so that it is no longer exposed to air or water. In addition, sanitary landfills are typically lined with an impermeable layer to prevent liquids from leaking into the groundwater.

**Disposal Safety Protects Everyone**

By following these safe guidelines for disposing of expired or unused medicines, everyone wins. When medicine cabinets are emptied of their clutter, it is much more than an exercise in cleanliness. Toxic chemicals are kept from entering into the food web of the world’s ecosystem, which we all are a part of — ourselves, our kids and our grandchildren.

**SARAH DEWEY** spent seven years as a community educator on the effects, storage and disposal of household hazardous products. She taught biology laboratory classes for 10 years at Missouri State University until common variable immune deficiency forced her to retire in 2008. She lives with her husband, two teenagers, one dog and four cats.

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**Disposing of IG Supplies and Bottles Used at the Home**

Since immune globulin (IG) medicines are infused in households by individuals, the waste produced is not regulated. Nevertheless, patients should follow the lead of professionals and treat these supplies as they would be treated at hospitals or infusion centers.

- Place used supplies, empty and partially full bottles of IG and any materials that come in contact with IG or bodily fluids, such as blood, in a “Sharps” or “medical waste” container at the end of the infusion.
- Keep Sharps containers closed.
- Keep Sharps containers out of the reach of children and pets.
- The pharmacy that provides the supplies probably will pick up and replace the container when it is full.

Note: Some state and local health departments allow used needles and empty IG bottles to be placed in the trash if they are in a sealed and labeled container. However, individuals will need to contact their respective agencies to find out what their local regulations allow.

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**References**


When it comes to managing health, it's no surprise if weight control is not the first thing on the minds of individuals with immune disorders. Taking care of family, home, work, doctors' appointments, infusion schedules and other responsibilities can leave these individuals so sapped of energy that the couch and the TV are far more inviting than pushing a grocery cart or standing over a hot stove. And, instead of planning and preparing meals, they may be more apt to grab whatever is easiest.

But, that lack of energy, coupled with medications, poor food choices and lack of exercise, can leave them with some extra pounds, draining them of even more energy.

**Lack of Energy: A Vicious Cycle**

Carrying extra weight increases stress on the spine and legs, which makes moving around more difficult — even for the healthiest of individuals. For those who already have decreased mobility because of neuropathy, multiple sclerosis...
or other debilitating diseases, even a few extra pounds can feel like a ton, making normal daily activities more difficult. “These problems can become a vicious, self-perpetuating cycle,” says John D. England, MD, FAAN, the Grace Benson professor and chair of the Department of Neurology, Louisiana State University Health Sciences Center in New Orleans. “Excessive weight further reduces activity, which then results in even more weight gain.”

“If someone is 50 pounds overweight, that is like continuously carrying around a 50-pound sack of flour all day,” says England. “Thus, the more weight that they can lose, the easier it will be for them to accommodate their disability and get around.” They can expect less of an energy drain as well.

Medications: An Added Challenge

A lack of get-up-and-go may not be the only thing contributing to stubborn pounds. Many of the common medications used to treat immune disorders increase the likelihood of gaining weight. Antidepressants such as amitriptyline and nortriptyline, antiepileptics such as gabapentin, and steroids such as prednisone frequently cause weight gain unless dietary changes are made, says England.

Excess fat does more than just weigh people down. Body fat is not inert. Instead, fat tissue secretes a variety of hormones and growth factors into the bloodstream that can affect both immune function and inflammation. Overweight and obesity are strongly linked to type 2 diabetes, heart disease, sleep disorders, certain cancers and otherwise preventable complications and hospitalizations not directly related to immune disorders. Studies suggest that obese individuals have a 50 percent to 100 percent increased risk of death from all causes compared to individuals of a healthy weight. Most of the disproportionate risk is attributable to heart disease.1

Many of the medications hindering weight-loss efforts also increase blood cholesterol and blood glucose levels, pumping up the risks for heart disease and diabetes even more. For example, it’s not uncommon to see blood glucose numbers jump from a healthy level to the pre-diabetes or even diabetes range shortly after starting prednisone. These troublesome side effects are more reason for individuals to carefully watch their weight.

Nutrition: Universal Mistakes

Achieving and maintaining a healthy weight is difficult whether or not an individual has an underlying health problem. Each year, there are more people who are unsuccessful with their weight-loss attempts than there are successful dieters. Many things derail the best intentions, but there are a few seemingly universal mistakes. Here are four common slip-ups and their solutions.

Too many liquid calories. Americans get about 20 percent of calories from beverages.2 Part of the problem is that these liquid calories don’t do much to satisfy hunger. Rarely do people compensate for the calories in drinks such as in sodas, juice, punch or fancy coffee drinks as they do for the calories they eat. But, one extra can of soda daily at about 150 calories piles on about 15 pounds at the end of a year. And, with super-sized cups and free refills, it’s not uncommon to drink 400 or more calories in one meal.

Solution: Think before your drink. Focus on calorie-free beverages like water, unsweetened tea and coffee. Limit beverages with added sugars like sodas, lemonade and punches and even those with natural sugars, such as 100 percent fruit juice. Even with all their nutrients, juices still pack on the calories without taming hunger. Be careful about what is added to coffee and tea, too. It’s possible to morph a virtually calorie-free drink into a calorie monster. Some whipped cream and a couple pumps of syrup can quickly add up to 200 or more calories. Water can’t be beat for hydration and for quenching thirst. To zip up its taste, try adding a little extra flavor from squeezed lemon or lime or a sprig of mint.

Different days mean different habits. Working hard Monday through Friday deserves reward but not a weekend diet reprieve. It’s pretty easy to undo a week of calorie savings in a couple of days that are filled with large restaurant meals, pizzas, a few drinks with friends and more desserts than usual. Moreover, a lot of people get tripped up by thinking that they’re not eating much on the weekends because they may skip a meal or just nibble throughout the day. But less food doesn’t necessarily mean fewer calories. A typical dinner in a chain restaurant can cost upward of 1,000 calories, and that’s even without dessert.
Solution: Make sure that the occasional splurge is really only occasional, and practice consistency from day to day. Researchers involved with the National Weight Control Registry found that those who maintain their food habits day after day are the most likely to maintain their weight loss.4 “Individuals with an immunodeficiency learn to become consistent with taking their medication and scheduling their infusions because they understand the negative consequences of not doing so,” says Matthew D. Hansen, DPT, of Auburn, Wash. “The same kind of faithfulness can be demonstrated toward exercise and healthy eating.”

Another part of the solution is choosing more healthful rewards. Getting through a difficult week of work and family obligations does deserve a treat, so individuals should be certain to schedule some enjoyable time just for themselves. It might be a few minutes of quiet time outside, a card game or movie with a family member, a good book or anything that brings them pleasure. And, while they should try to do this every day, they should make it a firm rule to take this time for themselves several times each week.

Eating more than you realize. Portion sizes at home and in restaurants are much larger than they used to be. For example, between 1977 and 1996, the average cheeseburger grew from 5.8 ounces to 7.3 ounces.5 During the same time, the average daily intake jumped by 168 calories for men and 335 calories for women.6 This swelling of portions and caloric intake coincided with a doubling of the obesity rate. By not paying close attention to the quantity of food they consume, individuals might be undoing their other efforts.

Achieving and maintaining a healthy weight is difficult whether or not an individual has an underlying health problem.

Eating while distracted contributes to increased quantities as well. Watching TV with a bag of chips makes it hard to know just how much is being eaten. Snacking while cooking or cleaning is another way to lose track of calories.

Solution: It’s time for individuals to examine their portions. They can start by cutting back just 10 percent of their meats, starches and desserts. To discourage second and third helpings making their way onto the dinner plate, serve the food from the kitchen instead of the table. Also, they should make a house rule to eat from a dish only — no bags, boxes, cartons or fists. Before eating chips or cookies, a reasonable portion should be served on a plate and the opened package should be put away.

Being way too strict. Sometimes when people make the decision to lose weight, they’re a little too gung-ho and very impatient. Setting unrealistic goals can lead to diet failure. Most people can follow a strict diet for a few days to even a few months, but few people can commit to such a plan long-term. There are food cravings, feelings of punishment or deprivation, and sometimes even social isolation if the plan doesn’t permit them to eat out or enjoy food with others. That’s when it falls apart, and strict dieting gives way to old habits or binge eating.

Solution: Be patient. The speed at which an individual loses weight is far less important than actually losing the weight and keeping it off. In fact, experts at the National Institutes of Health (NIH) recommend a weight loss of 10 percent in about six months, followed by a period of weight maintenance, before additional weight loss is attempted.7

Instead of following a particular weight loss plan or giving up favorite foods, individuals should identify small changes they know they can live with. If desserts are the biggest weakness, they shouldn’t be sworn off. Instead, practical, reasonable ways to limit sweets should be examined. For example, just two or three things can be eliminated to start, with more added as is comfortable. Also, vague goals like eating better, adding more fruit, eating less fried food and getting exercise should be avoided. Instead, it’s better to start with broad ideas and make them more actionable and specific:
• “Eating better” might become eating three meals each day and having snacks only when hungry.
• “Adding more fruit” becomes more specific and practical when saying that at least two pieces of fruit each day will be added. Or, individuals might decide to not eat dessert until at least two pieces of fruit have been eaten.
• “Eating less fried food” could mean a goal of eating fried foods no more than once weekly or three times monthly.
• “Getting exercise” is more likely to yield lasting results by starting with a goal of walking five minutes daily or doing water aerobics twice weekly.

Individuals need to take a close look at their diet and other health habits. What would they like to change? How can they do that? Goals should be specific, reasonable and something that can be quantified. For instance, each of the above goals is specific and measurable. Whether or not they are reasonable depends upon the person making them. Individuals will know if they ate two pieces of fruit each day last week or if they met their goal only five times. If goals aren’t specific, reasonable and measurable, they need to be refined until they are.

Exercise: The Other Component

According to the Diabetes Prevention Program (DPP), a study sponsored by the NIH, individuals should strive for 150 minutes of exercise each week. They should start small and build up to what is a reasonable level of exercise for them. Hansen suggests individuals consult with their doctor before beginning an exercise program. And, he recommends training with a physical therapist or a qualified certified athletic trainer who is familiar with their specific diagnosis. Chair exercises or walking may be good places to start. If individuals have energy levels that are really low, or secondary health complications, they should be sure to walk with a friend and use any necessary adaptive equipment such as a walker or crutch, he warns.

The Perfect Weight: Be Realistic

Being model-slim or reaching someone else’s idea of the perfect weight does not have to be the goal. Even a small weight loss can lower risk of further disease, help fight infections and improve mobility. For example, according to the DPP, a modest loss of about 7 percent of total body weight can significantly lower the chances of developing type 2 diabetes. If an individual weighs 170 pounds, that’s about a 12-pound loss. For someone weighing about 220 pounds, it’s about 15 pounds.

Taking Personal Control

Treating the whole body and not just the primary disease is critical, says Neil L. Kao, MD, allergist and immunologist in Greenville and Spartanburg, S.C. Kao says he asks his patients what their weight is, whether they are eating right and whether they are getting some exercise. “These are fundamental things that will help you stay healthier for longer, help you fight one infection after another.” But it’s no easy task to control weight, he acknowledges. Some medical conditions can leave people feeling exhausted even when they haven’t left the house. “Metabolically they might be running a marathon,” so it’s no wonder they’re not up for a daily walk.

But, managing weight is beneficial even beyond physical health. Taking control of any problem that seems out of control is empowering, and weight issues are no exception. Additionally, a better mood, improved eating habits and a little weight loss can boost energy levels, leading to a positive cycle of better health habits and even more energy.

For additional help, contact a registered dietitian. A geographical listing of dietitians can be found at www.eatright.org.

JILL WEISENBERGER is a registered dietitian, certified diabetes educator, nutrition and health writer, speaker, spokesperson and culinary expert based in southeast Virginia. Her website, All That’s Nutrition, can be accessed at www.allthatsnutrition.com.

References

Rehabilitation and Myositis

Physical therapy can help to manage this inflammatory muscle disease.

By Michael O. Harris-Love, DSc, MPT

People with myositis may have significant functional limitations and disability despite appropriate pharmacologic treatment to reduce inflammatory damage to their muscles. The impairments associated with myositis often result in a loss of independent ambulation, difficulty rising from a chair, an inability to negotiate stairs, and diminished health-related quality of life. Therefore, meaningful outcome measures and effective therapeutic exercise remain important in the medical management of the disease.

The clinician who draws upon the research literature to help formulate a disease-specific exercise prescription will be sorely disappointed. No quality randomized clinical trials (Class III studies) have been conducted to determine the efficacy of exercise as an intervention for myositis, and no exercise-based observational clinical trial (Class II study) has featured more than 25 subjects. Given these limitations, how should physical therapists approach the examination and plan of care for the patient with myositis? Evidence-based practice incorporates the best available evidence with clinical expertise and patient values. I offer the following recommendations based on our clinical experience and insights gleaned from exploratory studies involving exercise and myositis.

Chronic Disease: Capturing a Moving Target

All physical therapy evaluations include a systems review and specific tests for the cardiovascular, integumentary, musculoskeletal and neuromuscular systems. However, the unique demands of the patient with chronic disease require an approach that differs from the usual model of medical care in which a precipitating event — such as an injury or acute exacerbation of disease — provokes symptoms. Serial strength assessment is a critical element of the evaluation of patients with myositis. In our clinic, we recommend quarterly visits for serial strength assessment to help us monitor muscle weakness secondary to disease activity and damage and alter the exercise regimen based on the findings.

The manual muscle test (MMT) is the most common form of strength assessment and is listed as a core set measure by the International Myositis Outcome Assessment Collaborative Study Group. The MMT has well-known limitations: The grading criteria are subjective and dependent on the strength of the examiner, and large muscle groups may experience a 40 percent decrease in strength before the impairment is detected with MMT. However, the MMT remains the “language” that clinicians use when discussing...
strength, and it has proven to be a valid measure of strength for individuals with frank muscle weakness.

In our clinic, we have tried to address the shortcomings of the MMT in a couple of ways. Since summed MMT scores are more reliable than individual MMT grades, we report the percentage change in the MMT score in our patient notes and communications with physicians. At the 2005 American College of Rheumatology/Association of Rheumatology Health Professionals Annual Scientific Meeting, my colleagues and I reported that the five weakest muscle groups in a cohort of 52 adult patients with polymyositis and dermatomyositis (based on MMT data collected by a single examiner) included the neck flexors, shoulder abductors, knee flexors, hip abductors, hip flexors, and hip extensors. We recommend use of the proximal muscle groups in summed MMT scores to capture the regions most affected by the disease and increase the responsiveness of the outcome measure. Our clinic has also elected to augment our strength assessments with dynamometry testing. But when should clinicians strive to use objective strength measurements, and what is the best dynamometry method to use?

Objective strength testing is indicated when a patient complains of strength deficits that you cannot detect on clinical examination, or for large muscle groups difficult to test using the MMT. Consequently, patients with large stature are natural candidates for strength assessment via dynamometry. Perhaps the most popular form of objective strength assessment is grip dynamometry. While grip dynamometry is relatively inexpensive, reliable and easy to use, it cannot be used as a proxy measure of strength in patients with selective muscle weakness. This is certainly the case for patients with inclusion body myositis given the disproportionate involvement of their wrist flexors and knee extensors. Isokinetic dynamometry, while relatively expensive, offers superior stabilization during testing and provides a variety of testing modes. However, the time needed to conduct an isokinetic test precludes the testing of multiple muscle groups, and it is difficult to position people with severe muscle weakness on the device.

Handheld dynamometers provide more flexibility and less expense in comparison to isokinetic dynamometers. However, handheld dynamometers suffer from the same limitation as MMT: The outcome is dependent on the strength of the examiner. This type of device will exhibit high precision but low accuracy when used for large or strong muscle groups. The ideal objective strength-assessment device for both strong and weak patients is fixed dynamometry. Fixed dynamometers feature a plinth that allows for easy patient access and non-elastic straps attached to a frame to provide stabilization during testing. In our clinic, we record the clinical data from our dynamometry tests in absolute values, values scaled to body weight, and as a percentage of predicted force.

**Progressive Resistance Training Paradox**

The contributors to muscle weakness in adults with myositis include disease activity and damage, the effects of aging on muscle mass and muscle atrophy secondary to inactivity. Exploratory clinical trials have shown that progressive resistance exercise is safe for people with acute and chronic myositis. Also, strength training has been successfully used to address the predictable decrease in muscle mass and power that is associated with sarcopenia. Successful exercise regimens depend on selecting the mode of treatment preferred by the patient and calculating the optimal exercise intensity. Multiple factors contribute to exercise intensity, but the most commonly cited element is load (i.e., the amount of weight lifted). Typical errors in the exercise prescription for strength training include using initial intensity levels that are too high or selecting low levels of intensity without a progression scheme.

The initial exercise intensity may be informed by dynamometry tests performed in the clinic or simple estimates of the one-repetition maximum (1RM) using submaximal loads. (An online 1RM calculator can be found at www.exrx.net/Calculators/OneRepMax.html.) In my experience, many clinicians and patients are either unfamiliar or uncomfortable with identifying the 1RM. To address this concern, my colleagues and I have created exercise intensity categories based on the functional ability of the patient (see Table 1). Using loads limited to the repetitions ascribed to each functional level will ensure that patients are engaging in strength training at the proper intensity to maintain safety and produce strength adaptations.

These intensity categories highlight the progressive resistance training paradox: High training intensity must be paired with low training volume, and low training intensity must be paired with high training volume. Strength training regimens at higher intensities require adequate recovery time for neuromuscular adaptations to occur, whereas strength training regimens at lower intensities require increased exercise volume to induce a training response and may constitute customary activity in the patients with severe muscle disease. Objective strength assessment is needed to identify optimal exercise intensity, and serial strength assessment is required to progress exercise intensity.
**Recognize the Hidden Impairments**

While muscle weakness is the most prominent impairment associated with myositis, it is important to not lose sight of the systemic, autoimmune etiology of this disease. Myositis is more than just a muscle disorder. The morbidity that results from myositis may involve the cardiovascular, pulmonary, gastrointestinal and integumentary systems (recommended rehabilitation outcome measures are listed in Table 2). Limitations in aerobic capacity may be due to capillary involvement in forms of inflammatory muscle disease such as dermatomyositis, or the result of inactivity secondary to muscle weakness.

The American College of Sports Medicine recommends aerobic activity at 40 percent to 85 percent of maximal oxygen consumption (VO2 max), 50 percent to 90 percent of maximal heart rate and 20 to 60 minutes in duration for three or more days per week (the range of values is designed to accommodate different levels of fitness).

Muscle abnormalities may cause measures of aerobic performance such as the rate of oxygen consumption, heart rate and respiration rate to underestimate the efforts expended by patients with myositis. Therefore, proxy measures of aerobic exercise intensity such as the Borg rating of perceived exertion (e.g., 13–14, or “somewhat hard” corresponds to 51 percent to 75 percent of VO2 max) or the Talk Test (i.e., difficulty speaking during aerobic exercise is related to the onset of anaerobic threshold) are patient-friendly tools that may be used to guide aerobic training regimens. Patients unable to exercise continuously for at least 20 to 30 minutes are encouraged to engage in multiple shorter periods of aerobic activity.

The secondary balance impairment that results from muscle weakness poses an additional barrier to aerobic fitness. Physical therapists should review aerobic training alternatives with their patients such as the recumbent stationary bicycle and upper-extremity ergometry. The initial

<table>
<thead>
<tr>
<th>Functional Status</th>
<th>Exercise Elements</th>
<th>Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking</td>
<td>Workload, Frequency, Sets, Reps, Mode of exercise, Environment, Assistance</td>
<td>Level 1: No gait aid use</td>
</tr>
<tr>
<td></td>
<td>Workload: Estimated 70% to 80% of 1RM</td>
<td>Estimated 70% to 80% of 1RM</td>
</tr>
<tr>
<td></td>
<td>Frequency: Three to four times per week, once per day</td>
<td>Three to four times per week, once per day</td>
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<tr>
<td></td>
<td>Sets: One to two sets per muscle group</td>
<td>One to two sets per muscle group</td>
</tr>
<tr>
<td></td>
<td>Reps: 8 to 10</td>
<td>8 to 10</td>
</tr>
<tr>
<td></td>
<td>Mode of exercise: Isotonic (free weights), functional training</td>
<td>Isotonic (free weights), functional training</td>
</tr>
<tr>
<td></td>
<td>Environment: Gym, home, outdoors, etc.</td>
<td>Gym, home, outdoors, etc.</td>
</tr>
<tr>
<td></td>
<td>Assistance: None required, may use training partner</td>
<td>None required, may use training partner</td>
</tr>
<tr>
<td>Assisted walking</td>
<td>Workload, Frequency, Sets, Reps, Mode of exercise, Environment, Assistance</td>
<td>Level II: Gait aid or orthotic use</td>
</tr>
<tr>
<td></td>
<td>Workload: Estimated 60% to 70% of 1RM</td>
<td>Estimated 60% to 70% of 1RM</td>
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<tr>
<td></td>
<td>Frequency: Four to five times per week, once per day</td>
<td>Four to five times per week, once per day</td>
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<tr>
<td></td>
<td>Sets: One to two sets per muscle group</td>
<td>One to two sets per muscle group</td>
</tr>
<tr>
<td></td>
<td>Reps: 10 to 12</td>
<td>10 to 12</td>
</tr>
<tr>
<td></td>
<td>Mode of exercise: Isotonic or isometric, elastic bands, safe functional training</td>
<td>Isotonic or isometric, elastic bands, safe functional training</td>
</tr>
<tr>
<td></td>
<td>Environment: Gym, home, clinic, outdoors on smooth surfaces</td>
<td>Gym, home, clinic, outdoors on smooth surfaces</td>
</tr>
<tr>
<td></td>
<td>Assistance: May be required at gym, clinic, outdoor activity</td>
<td>May be required at gym, clinic, outdoor activity</td>
</tr>
<tr>
<td>Motorized mobility</td>
<td>Workload, Frequency, Sets, Reps, Mode of exercise, Environment, Assistance</td>
<td>Level III: Motorized Scooter or Wheelchair Use</td>
</tr>
<tr>
<td></td>
<td>Workload: Estimated 40% to 60% of 1RM, or just body weight</td>
<td>Estimated 40% to 60% of 1RM, or just body weight</td>
</tr>
<tr>
<td></td>
<td>Frequency: Five to seven times per week, once or twice per day</td>
<td>Five to seven times per week, once or twice per day</td>
</tr>
<tr>
<td></td>
<td>Sets: Two to three sets per muscle group</td>
<td>Two to three sets per muscle group</td>
</tr>
<tr>
<td></td>
<td>Reps: 12 to 15</td>
<td>12 to 15</td>
</tr>
<tr>
<td></td>
<td>Mode of exercise: Manual resistance, isometric, elastic bands, active range of motion, assisted active range of motion, assisted functional training on a mat or at bedside (gravity-minimized positions)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Environment: Home or clinic</td>
<td>Home or clinic</td>
</tr>
<tr>
<td></td>
<td>Assistance: Assistance required for most exercise activities</td>
<td>Assistance required for most exercise activities</td>
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</tbody>
</table>
Session of upper-extremity ergometry should be closely monitored since it is about 25 percent less efficient than lower-extremity ergometry and has higher oxygen demands. Understanding the methods to monitor aerobic intensity and using creative approaches to exercise safely will allow the patient and physical therapist to craft an effective training program. By using serial strength assessments to monitor chronic disease, determining the appropriate progressive resistance exercise intensity, and being aware of the impairments of myositis that extend beyond weakness, physical therapists can play a valuable role in the clinical management of inflammatory muscle disease.

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Table 2. Rehabilitation Outcome Measures Based on the International Classification of Functioning, Disability and Health Domains

<table>
<thead>
<tr>
<th>Measurement Domain</th>
<th>Measurement Subcategory</th>
<th>Measurement Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body functions and structures</td>
<td>Strength</td>
<td>Manual muscle test (proximal subscore and total score)</td>
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<td></td>
<td></td>
<td>Fixed dynamometry</td>
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<tr>
<td></td>
<td></td>
<td>Estimated one-repetition maximum</td>
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<tr>
<td></td>
<td>Anaerobic fatigue</td>
<td>Fixed dynamometry</td>
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<td></td>
<td></td>
<td>Isokinetic dynamometry</td>
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<td></td>
<td></td>
<td>Childhood Myositis Assessment Scale (endurance tasks)</td>
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<td></td>
<td></td>
<td>Adult Myopathy Assessment Tool</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(muscle endurance subscale)</td>
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<tr>
<td></td>
<td>Psychosocial fatigue</td>
<td>Fatigue Severity Scale</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pediatric Quality of Life Inventory:</td>
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<tr>
<td></td>
<td></td>
<td>Multidimensional Fatigue Scale</td>
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<tr>
<td></td>
<td>Aerobic capacity</td>
<td>Submaximal cycle ergometry</td>
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<tr>
<td>Activities</td>
<td>Functional activities</td>
<td>Self-selected walking speed</td>
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<tr>
<td></td>
<td></td>
<td>Timed tests of function</td>
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<tr>
<td></td>
<td></td>
<td>Health Assessment Questionnaire</td>
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<tr>
<td></td>
<td></td>
<td>Childhood Myositis Assessment Scale</td>
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<tr>
<td></td>
<td></td>
<td>Adult Myopathy Assessment Tool</td>
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<tr>
<td></td>
<td></td>
<td>(functional subscale and total score)</td>
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<tr>
<td></td>
<td></td>
<td>Functional Index 11</td>
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<td></td>
<td></td>
<td>Myositis Activities Profile</td>
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<tr>
<td>Participation</td>
<td>Health-related quality of life</td>
<td>Medical Outcomes Study 36-Item</td>
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<td>Short-Form Health Survey</td>
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<td></td>
<td></td>
<td>Sickness Impact Profile</td>
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<td>Nottingham Health Profile</td>
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</tbody>
</table>

References

Reprinted with permission from The Rheumatologist.
Carolyn Spooner first noticed that she had trouble using her left hand to hit “control, alt, delete” on her computer while at work. But since it was only her middle finger that was numb, and Spooner is right-handed, the business systems analyst didn’t think it was a big deal. “We figured it was a pinched nerve,” she says. A few months later, in January, she started having gesticulations in her left arm. “They weren’t uncomfortable, but odd enough to make me nervous,” she says. It got progressively worse, and by May, her hand was almost nonfunctional. When she put her palm flat on a table, she could move only her pinky. “I had no idea what the problem was and because it didn’t hurt, it didn’t make sense to me at all,” she says. The doctors tried nerve release surgery and other treatments, but nothing worked. The Candia, N.H., woman was shuffled from specialist to specialist in hopes of learning the cause of her numbness. Then, she stumbled upon a neurologist who thought he knew what the problem was. “He said he’d heard about it, read about it, but never seen it,” Spooner says. His diagnosis: She had multifocal motor neuropathy, a disease of the peripheral nerves, arms and legs.

What Is Neuropathy?

Neuropathy is a degenerative condition of the nervous system or the nerves. People with autoimmune disorders are more prone to peripheral neuropathy, which occurs when tissue in the peripheral nervous system — the communications hub that carries information from the brain and spinal cord to the rest of the body — comes under attack. Three types of peripheral nerves are affected: sensory nerves, which help with sensation; autonomic nerves, which assist internal organ functions; and motor nerves, which work with muscles.

Damage to the peripheral nervous system can interfere with the signals between the brain and the rest of the body. This damage can be caused by more than 100 types of peripheral neuropathy, each with its own set of symptoms and treatments. For people with autoimmune disorders, some common peripheral neuropathies include chronic inflammatory demyelinating polyneuropathy (CIDP), Guillain-Barré syndrome (GBS) and multifocal motor neuropathy (MMN). CIDP and MMN come about from immune system activities rather than from direct damage by infectious organisms, whereas GBS is believed to be brought on by a virus. All three
of these peripheral neuropathies also are demyelinating diseases, which means they destroy myelin, a fatty protein that protects many nerves. When the myelin is damaged, nerve impulses slow or even stop, resulting in neurological deficits.

CIDP has numerous symptoms that include muscle weakness, numbness and pain in the extremities, impaired balance and difficulty walking. The disease usually starts in the legs but can also begin in the arms. It can cause severe weakness and even death if left untreated. CIDP may have patterns of remission and relapse, but most patients will require some form of therapy for life. Although there is no cure for CIDP, it is treatable with corticosteroids. Some patients who don’t respond to steroids or suffer from their side effects can use alternative drugs such as mycophenylate. Patients often see dramatic improvement with a therapy regimen with intravenous gammaglobulin (IVIG).

According to GBS/CIDP Foundation International, Guillain-Barré is the most common cause of rapidly acquired paralysis in the United States today, affecting one to two people in every 100,000. GBS has similar symptoms to CIDP, except GBS has a more sudden onset that often requires immediate hospitalization. Most reach the stage of greatest weakness within the first two weeks after symptoms appear, and by the third week, 90 percent of all patients are at their weakest, the National Institute of Neurological Disorders and Stroke says. If GBS doesn’t get better or becomes a chronic issue, it is often rediagnosed as CIDP. GBS is treated with plasma exchange and high-dose IVIG. Once a GBS patient recovers, the disorder typically doesn’t return.

MMN is a progressive muscle disorder characterized by muscle weakness in the hands. Unlike CIDP and GBS, MMN affects only the nerves’ motor fibers — not the sensory fibers — so there’s no numbness or pain. MMN’s symptoms include muscle wasting, cramping and involuntary contractions or twitching of the leg muscles. The disorder is sometimes mistaken for amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease), but unlike ALS, it’s treatable. Some patients have mild symptoms and require no treatment. Most receive IVIG as the first course of treatment, with 80 percent of patients showing improvement after the infusion, according to the Multifocal Motor Neuropathy Center at Johns Hopkins. An early and accurate diagnosis allows patients to recover quickly.

CIDP is the most common of the conditions, followed by GBS and MMN, according to Dr. Carol Koski, medical director of the GBS/CIDP Foundation International. “In all three of these disorders, there tends to be a male predominance — not quite a 2-to-1 male-to-female ratio,” Koski says.

A Difficult Diagnosis

It’s often not easy to diagnose peripheral neuropathy, and in most instances, the patient doesn’t realize there is a real problem. In Spooner’s case, she later realized that she had other MMN symptoms that she ignored at the time. “I was extremely fatigued. I was taking three- or four-hour naps on the weekends,” the 54-year-old says. “I had no idea that had anything to do with my hand. I knew I was having trouble with my legs before I could prove it. I would walk with [my] dog, Piper, and it got to be that walking through uneven ground or snow was a problem.”

Julienne Dallara wasn’t hit with an onslaught of symptoms when she was diagnosed 13 years ago. “For a couple of weeks, I felt strange,” she says. “I knew something was wrong, but I couldn’t tell what. One morning, I couldn’t urinate. So I went to my obstetrician, because that was the only doctor I had,” says Dallara, who was a new mom at the time. Her obstetrician referred her to a neurologist, who then sent her to the hospital. “The next morning, I woke up in the hospital paralyzed from the waist down,” she says.

People with autoimmune disorders are more prone to peripheral neuropathy, which occurs when tissue in the peripheral nervous system comes under attack.

Dallara was diagnosed with transverse myelitis, a neurological disorder caused by inflammation across both sides of one segment of the spinal cord. Three years later, she also was diagnosed with CIDP. “They tried all kinds of stuff when I was in the hospital, but nothing seemed to change; I couldn’t feel anything from the waist down.” After 10 days in the hospital, she was transferred to a rehab facility so she could learn to live in a wheelchair. “They thought I would make a relatively full recovery because most people with myelitis do,” she says. She went home with a wheelchair and walker and was working on getting better. Then, two months later, she had a relapse and became completely paralyzed from the waist down and couldn’t stand up for four or five months, until she received chemo. “That got me back on my feet again,” she says.
Treating Peripheral Neuropathy

Dallara’s immune system is hyperactive and it attacks her body, including the myelin of her spinal cord. To stay healthy, doctors have to keep depressing her immune system. “They don’t know what’s causing it, or why,” the Los Angeles resident says. “So for the last 13 years, I’ve been trying to keep the symptoms under control.” To do this, she gets an infusion of IVIG every three weeks. “The way it makes sense to me is that in order to keep from being paralyzed, I can either destroy all the bad guys or I can flood my body with so many good guys that they outnumber the bad guys,” she says. “By doing chemotherapy, we are killing the bad guys, but it’s hard on me as well. What IG does is flood my body with good guys. It does that for a while and I can keep on going.” She also takes medication to manage the pain. The first couple of years, she didn’t have painful neuropathy, just paralysis, but over the years, the burning, buzzing and banding feeling — “like someone’s wrapping Saran wrap really tightly around my leg,” she says — has gotten worse.

Spooner also uses IG to alleviate her symptoms. “If I don’t have the IG treatment every four weeks, I immediately notice an increase in fatigue and start to lose ground in my hand,” she says. “The IG has taken care of the hand problem, but I have more trouble now with my legs.” To help her walk, she takes muscle relaxants regularly to control muscle spasms.

In addition, both Spooner and Dallara look for nonmedical ways to cope with their neuropathies. “I have found that the way for me to deal with it is to keep so busy that I don’t notice it as much,” Dallara says. “If I start to pay attention to it, it gets worse. I have noticed that when I get stressed, it gets worse.” However, she also has to be careful to not overdo it. “The job I’m in is very demanding, and the hours are long,” says the 49-year-old, who sells handicapped vehicles. “It’s not unusual to work a 12-hour day. It helps keep my attention off the pain, but it makes the pain worse when I stop. It’s a balancing act.” Spooner tries to work around her condition by planning her days carefully. “I work full time and I have to not plan anything in the evenings,” she says. “If I’m out one night and I go to bed early the next night, I really need two or three nights to make up for the first night.” Spooner also exercises regularly, focusing on building her core to help with her walking, and tries to eat well, cutting out diet soda and limiting sugar.

Both women picked up hobbies that don’t require mobility or a lot of physical strength. Spooner has gotten into genealogy and knitting. It was particularly hard for Dallara to stop being as physically active, since prior to her paralysis she was an actor, singer and dancer. But she found creative outlets in oil painting and jewelry making.

Coping with Neuropathy

For those newly diagnosed with a neuropathy, Spooner advises them to find out what they can about their disease. But, she warns that they shouldn’t be disappointed when the answers are, “Everybody’s different” or “We don’t really know.” “You have to recognize the reality of the situation, but you also have to believe that there are going to be good days and that there are things you can do,” she says. “A positive attitude makes a big difference.” She also gets her own copies of tests and records and keeps it all in a three-ringed binder, which she brings to appointments so that she’s always prepared. Another thing that Spooner finds helpful is listening to meditation tracks on her iPod to help her relax. “They re-energize me,” she says. She also takes power naps during the day, sometimes ducking into an empty conference room at work to catch some z’s. “It gives me the boost I need to get through the day,” she says.

Dallara maintains that it’s important to keep trying to get better. “In my line of work, I see people with many different disabilities, and I’m seeing more and more people diagnosed with neuropathy each year,” she says. “More and more people are coming into my office saying, ‘I’m in a wheelchair because I have neuropathy,’ or ‘I’m on a scooter because I have neuropathy.’ It’s not an excuse to stop living. Keep pushing for more and more that you can do.”

Jennifer Kester is a San Diego-based writer and editor specializing in health and lifestyle issues.
Ask Kris

By Kris McFalls

**Reader:** Before I became eligible for Medicare, I was using Gamunex subcutaneously for common variable immune deficiency (CVID). Now that I am eligible for Medicare, my provider would like me to switch to Vivaglobin. I have been told that Medicare may not approve subcutaneous immune globulin (SCIG) for any other product. In addition to CVID, I am also IgA deficient. Should I be concerned about the IgA content in Vivaglobin?

**Kris:** If you have not already done so, you should talk with your physician who prescribes your infusion, as well as your primary care physician, to make sure nothing else is going on. Also, keep a health diary of your symptoms and record when they occur in relation to your infusions. This will help your doctor determine if this is a reaction to the infusion or something else. To read more about side effects of Gammagard, go to [www.gammagard.com](http://www.gammagard.com) and click on prescribing information. To address your question further, I asked a pharmacist experienced with IG therapy to address your concerns.

**Pharmacist:** Some patients may experience allergic reactions to every dose of IG, while others may experience episodic allergic reactions. Often, pre-medication with antihistamines or corticosteroids is helpful in preventing allergic reactions. If patients still experience allergic reactions with a particular brand of IG, despite pre-medication or treatment with antihistamines, then an alternative brand of IG may be tried.

**Question:** Why do my lab work results frequently come back normal when I have an infection?

**Kris:** I hear from many PIDD patients who say they have lab work that just does not seem to match the way they feel with an infection. I passed along your question to Dr. Melvin Berger for an answer.

**Dr. Berger:** The results of lab work depend on what infection is present and what the actual underlying condition is. In some patients in whom signaling pathways do not function properly, the body does not recognize or respond to infection normally. This may include a lack of fever despite a serious bacterial infection, which might be accompanied by a lack of laboratory signs of infection. The most outstanding example of this would be the extremely rare condition, IRAK-4 deficiency. Also, many times viral infections do not alter lab work. In many patients, infections that are in the bronchial tubes or sinuses may cause symptoms at those sites but might be invasive enough to provoke a systemic response. The same is often true in some chronic fungal infections.

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**Kris McFalls** has two adult sons with chronic diseases treated with IG. She is formerly a physical therapist assistant, and currently is IG Living’s full-time patient advocate.

Melvin Berger, MD, PhD, is professor of pediatrics and pathology at Case Western Reserve University.

Hans D. Ochs, MD, is a professor of pediatrics and is the Jeffrey Modell Chair of Pediatric Immunology Research at Seattle Children’s Research Institute Center for Immunity and Immunotherapies.
Let’s Talk!

By Trudie Mitschang

If your life depends on immune globulin, this column is for you! Here, we have an opportunity to network and share our experiences about all of the ramifications of our illnesses, and to learn from one another. If you have a question, comment or experience to share for a future column, email it to us at editor@IGLiving.com.

In this issue, we chat with John Crawford, 65, and Debbie Crawford, 52, who both suffer from stiff person syndrome (SPS), a rare disorder affecting only one in one million people. Prior to the advent of the Internet, the odds of John and Debbie meeting, much less falling in love, were on par with contracting the disease — one in a million. But thanks to technology, John and Debbie will celebrate their second wedding anniversary this year. Their story will be featured in the latest edition of the popular Chicken Soup for the Soul series titled “True Love.”

Trudie: Since both of you have

include intravenous immune globulin (IVIG) and plasmapheresis, as well as pharmacological therapy. Some also may benefit from behavioral and physical therapy.

Trudie: Tell me how the two of you met.

John: I was widowed shortly after I was diagnosed with SPS; doctors had given me two years to live. I began treatment with IVIG and miraculously began to get better. I met Debbie when I was searching online for support groups and came across her website. Her story moved me and I sent her an email with my phone number. A few weeks later, she contacted me and we became very close friends.

Debbie: When I met John, we had an instant rapport and shared a lot of things besides our SPS — it wasn’t just commiserating and complaining. We have a similar “gallows” sense of humor, and we were friends for four years before finally meeting face to face in August 2007. My previous marriage had failed, and I was cautious about a new relationship. Plus, we really had to come to terms with the fact that both of us having SPS could be a tremendous challenge; we didn’t want to be a burden to one another.

Trudie: What are the symptoms of SPS and how is it treated?

John: SPS is a rare disease of the nervous system. The symptoms include progressively severe muscle stiffness in the spine and lower extremities and painful episodic muscle spasms that can come on suddenly. Most people with SPS have other autoimmune disorders as well.

Debbie: There are variances in the symptoms of SPS. Treatments

In the story “Go For It,” Debbie shares her thoughts about how to be disabled without letting disability define you.
chronic illnesses, who is the caregiver in your relationship?

**John:** We take turns. In addition to SPS, Debbie is a type 1 diabetic and I have chronic inflammatory polyneuropathy (CIDP). I also have heart problems, so we don’t know what the future holds. But we are committed to making the most of every moment.

**Debbie:** Between the two of us, our calendar is peppered with doctors’ appointments, which we turn into lunch dates! I help him button his shirt, and he helps me put on my pantyhose; so it’s give and take all the way. With our combined ailments, we buy our medications in bulk, and then there’s all of our medical equipment, gait aids and handicapped placards. We understand our reality and limitations, but our motto is: “The only future is the day.” We make the most of each one.

**Trudie:** SPS can be very debilitating. Tell me about some of the issues and how you have overcome them.

**John:** People look at us and assume we are so in love because we are always holding hands. The truth is: We are holding each other up!

**Debbie:** Fear of open spaces is a common concern. With SPS, your muscles can just lock up unexpectedly, which can be terrifying if you are crossing a busy intersection or riding an escalator. For me, it was a matter of facing the issues head on.

**Trudie:** How do you pay it forward?

**John:** I always look for opportunities to help others. We’re very involved in our church, and we have a nursing home ministry where we visit the seniors once a month.

**Debbie:** I pay it forward through my website outreach with information, a personal perspective and hope. I love to post silly pages that make people laugh. Sharing a smile with others is such an easy thing to do, but it can make a huge difference in someone’s day.

**Trudie:** You both have a great sense of humor. What makes you laugh?

**John:** SPS is a bizarre syndrome. Finding humor in some of my quirky situations is a positive way I cope. Laughing at yourself helps you become better, not bitter.

**Debbie:** I find humor in children and reality. Like John, I look for the laughter instead of tears with my SPS. We find humor in each other.

**Trudie:** How has IVIG helped you?

**John:** I’m just starting with IVIG again, and it’s been a tremendous help to me. Now I am able to walk around the block.

**Debbie:** IVIG has helped us tremendously. Even though it’s not a cure, it can really improve your quality of life and should be available to anyone who needs it.

**Trudie:** What are you looking forward to?

**John:** Loving Debbie as long as I can. I never dreamed I would remarry, so I’m very fortunate. One thing I said many years ago is it’s not what kills you that amazes me, but it’s what you can live with and still survive. Here I am with five illnesses and able to do as much as I do; Debbie has made me a stronger, more vital human being.

**Debbie:** I want as blessed and full a future as I can have. I have been encouraged to write. I want to enjoy my children and grandchildren. John and I know our lifetime is just a season. We choose to make it Christmas.
The Little Pancake That Could

By Cheryl L. Haggard

THE SAPPY SWEET smell of gently warmed maple syrup and hickory-smoked pan-fried bacon slowly wafts through our house announcing breakfast treats are almost ready. The first swig of coffee coats my tongue as the sizzle of a well-seasoned griddle laden with tangy buttermilk batter invites the troops to gather ’round. Three sleepy bed-heads watch bubbles rise from the cooking pancakes in anticipation of a solitary flip from my favorite red spatula, signaling our Saturday morning tradition is ready to ingest, nourish and delight.

I rejoice as my three PIDD kids wolf down the breakfast I’ve prepared almost the same way for the last 12 years; it hasn’t always been this easy trying to get three very sick children to eat something — anything. All night long, as they tried to rest between bouts of fevers, wheezing, stuffy heads and sneezing, I swore the immune deficiency they fought stole their desire for food. Until I tried pancakes.

Who knew that this simple and time-honored breakfast staple would become the answer to what ails, and what fills, their tummies better than the green goop draining from infected sinuses? But, these have not always been ordinary pancakes. At first, Molly ate only Mickey Mouse, Calvin ate only kitty cats and doggies, and Caleb, only trains and airplanes. But, oh so cute! I’d use fat chunks of bananas for wheels, raisins for button noses and chocolate chips for eyes. My
griddle produced works of art and entertained my family. I even made a football for my husband, Mark, once; hunger beat humiliation as he smacked and the kids giggled — all the while nourishing happy memories and chronically ill bodies.

My present-time PIDD kids still savor our Saturday morning tradition; however, pre-pubescent maturity has, alas, stripped me of creating innocent forest animals and The Little Engine That Could out of Bisquick. It’s bittersweet: I bake boring circles with my batter, but at least I have three medically stable mouths to feed (thanks to their immune globulin). And until a recent school project, I had relinquished all hope ever to bake into existence precious pancake critters again.

Our children go to a public math and science magnet school. I love the kids’ school, despite the jeers and jokes I endure.

“Cheryl, there’s a reason you only taught first grade!” teased my longtime friend and former teaching partner, Sue.

“Yeah, I know. I just want the best for my kids,” I sulked.

“And who, pray tell, is going to help them with their homework?” Sue continued. I shot a puppy dog look Sue’s way and she responded with, “And good luck to you!”

Despite the kids asking me not to help with math (thankfully), science projects are how I roll. So, when Calvin came home with a difficult, but close-to-all-of-our-hearts’ theme — the human immune system — I told Sue, “I can finally help with homework!”

But, as Calvin and I dug deeper and deeper into the immune system and I don’t know how many pounds of homemade salt modeling clay (read, total science project insanity!), his project’s due date loomed and I hung my head and confessed to my hopeful boy, “Calvin, I’m making a mess of your project.”

Calvin’s bright hazel eyes glazed over in disbelief. I was letting my boy down and borderline teaching him how a quitter behaves.

“It’s OK, Mom,” Calvin consoled me as he put a reassuring hand on my shoulder. “Maybe we bit off more than we can chew,” he said as he rolled a salt clay ball between his fingers.

“Speaking of chewing, I’m hungry. When’s dinner?” Calvin asked, dissolving the depressive defeatist cloud over both of our heads.

At the moment, I wasn’t thinking about my nightly motherly chore; I was brooding over how to create 3-D B cells, T cells and other cells that Spell Checker doesn’t recognize.

Just then, the kitchen clock and three “little birds” with their mouths open wide in anticipation told me I needed to put the phagocytes away and feed my brood.


I fixed upon a box; its familiar lettering and comforting colors drew me closer. If it had the ability to speak, it would say, “I’m the answer to all of your problems.”

“Calvin, get the griddle. Caleb, the syrup, eggs, butter and milk. Molly set the table ‘cuz we’re havin’ pancakes!”

The dark cloud lifted as my brood sang praises about breakfast for dinner. Everybody was happy, celebrating our bounty.

As I ladled the first boring circle of batter, a deep ache for the pancakes of days long gone haunted me: bunnies with banana ears, kittens and doggies donning chocolate chip noses, and choo-choo trains billowing luscious whipped cream from a smokestack. It’s all just sweet memories now, I sulked.

I began doodling with pancake batter in a naked corner of the griddle. Ha ha, a snake! I thought: They can take my momentary sanity, my sleep and run up the insurance bill, but they cannot squelch my creativity!

“What’s that thing in the corner? It looks oddly like a granulocyte!” Calvin muttered, his voice rising with excitement.

“It does!” I squealed with joy. “And that one over there looks like pneumococcus!”

Two hours later and a box of Bisquick emptied, my griddle had germs and immune cells of all kinds sizzling away. And by night’s end, Calvin’s science project was a complete success.

A few days later, Calvin came home sporting an A minus on his immune system project and a note from his teacher: “Dear Mrs. Haggard: Would you be willing to help in class on Thursday? Bring your griddle.”

CHERYL L. HAGGARD is a stay-at-home mom and has three children, two of whom have CVID. She and her husband, Mark, also operate Under the Hood Ministries at www.underthehoodministries.org.
UPON THE PASSING of my father-in-law, who lived with common variable immune deficiency, we inherited his beloved telescope. My son, Caleb, took a liking to gazing at the stars. During the summer, he had it set up in the backyard. And, a few days ago, we noticed part of the mesh screen was cut out of his window so he could have an unobstructed view of Orion and Ursa Major.

It reminded me of a recent study of Tycho Brahe in history class. Tycho (as he is referred to most commonly) was a Danish astronomer of the 16th century. His research, along with that of Galileo and Copernicus, created the study of modern astronomy, moving society out of the Dark Ages of myth and superstition into the modern scientific age.

But there was more to Tycho than determining the distance between the Earth and the sun or deriving theories of planetary motion. Tycho had a torrid temper. During a deep discussion, another astronomer challenged Tycho’s scientific conclusions. Not one to be challenged, the Dane grabbed a sword and a duel was on. During the course of the “debate” that followed, Tycho lost most of his nose.

In the days before plastic surgery, little could be done to repair major organs that had been lopped off — unless you were wealthy like our Danish astronomer with the hot temper. Rather than have his nose reconstructed, Tycho went to his local goldsmith, who fashioned a new “schnoz,” composed completely of the precious yellow metal. And, he soon became as famous for his 14-carat nose as he was for his astronomical discoveries.

One evening, while watching Caleb adjust the focus on his telescope, I noticed him rubbing his nose. That was it! If I believed in reincarnation, I would be certain he had been Tycho Brahe in an earlier life. I considered how much a nose the likes of the Danish astronomer’s would cost and how much money we had poured into medical costs for my son.

As I watched Caleb move the telescope ever so slightly, my mind drifted back eight years to a hospital recovery room where my then 2-year-old son lay quietly with bandages across his face. “This was cool,” Dr. Lienert told us gleefully after Caleb’s first sinus surgery. “I got to use this $200,000 virtual reality camera to do his surgery. It was like I was actually walking around up in his maxillaries!”

My wife and I have a convoluted (perhaps sick) habit of seeing how much our insurance is paying out on certain procedures that are performed on our family members. “Hey,” my wife called, holding up an all-too-familiar envelope one afternoon following a trip to the mailbox. “This must be from Caleb’s sinus surgery at ‘U-Dub.’”

“How much was it?” I asked.

She opened the envelope and muttered, “Goodness gracious! What did Dr. Lienert use? Gold?”

It was the fifth surgery in Caleb’s young life. We were given strict instructions on how to care for his $100,000 nose: sinus washes, nose spray, antibiotics and the like. We decided to help him recover by making tacos, one of his favorite dinners. Halfway through the meal, he sneezed and got a chunk of ground beef stuck in the back of his sinuses. He squinted and grabbed his nose trying to dislodge the object. “Careful, son,” I called. “There’s a gold mine up there.”

The similarities between Tycho Brahe and my son Caleb do not end with their comparable schnozes and interest in the stars. Tycho had a student, Johannes Kepler, who borrowed the work and the conclusions of his teacher to craft an even more credible theory of the universe. In our own family, it is Molly, Caleb’s sister, who has benefited from the slings and arrows of his outrageous fortune. Doctors have borrowed the conclusions of Caleb’s tests to make a quick diagnosis of Molly, sparing her a golden nose of her own. It’s our hope that doctors also can borrow the conclusions of Caleb’s tests to make a quick diagnosis of other children as well.

MARK T. HAGGARD is a high school teacher and football coach, and has three children, two of whom have CVID. He and his wife, Cheryl, also operate Under the Hood Ministries at www.underthehoodministries.org.
THE DOWNFALL OF the economy during the past year has resulted in tough times for all — with layoffs, debt accumulation and lost insurance coverage. Many are faced with making sacrifices, so I know I am not alone when struggling to make choices about the way I spend the little money I have. But if there is a segment of the population that is being hardest hit, it is those of us on disability who rely on fixed payments.

I pay my bills first, but like most, I get that urge inside that is connected to my wallet. Those are the times when I stroll past a store window and see the most amazing pair of flat, knee-high soft-as-butter boots that I just have to have! But wait!! I haven’t been to the pharmacy yet to pay for and pick up the refills for five different medications. And, I still have that appointment next week with a $25 co-pay, not to mention the very likely chance that my doc may order a procedure like a CT scan that will put me out another $50. What to do?

Many people battle with doing the right thing versus giving into instant gratification. But, for those of us who have the added financial responsibilities for treating our immune diseases, such conflicts are about whether to be healthy and live comfortably, or just do what feels good in the moment and worry about our health when our conditions worsen. Looking at things in this light makes one wonder why such choices are so hard.

I remember when I was younger watching cartoons and there was an angel on one of Daffy Duck’s shoulders and a little devil on the other. At the time, I had no idea what a conscience was, but I knew that the angel did the right thing and the devil tried to get Daffy to do the terrible, yet instantly gratifying thing — like eat the entire cake sitting in front of him — ‘cause it was soooooo good! Now I understand why it was so hard for him to choose. Too often, I hear that little devil whispering in my ear: “Just buy the bag; it may not be here a month from now when you have money. It looks fabulous on you!” Sometimes I am weak and I give in, but it’s so obvious after the fact that I made a bad choice that I come to my senses and make the return.

Perhaps the struggle with our health puts us a bit out of touch, or maybe it places us too close to reality or gives us this sense of feeling sorry for ourselves and willing to give ourselves something we shouldn’t have. Does having this added responsibility for keeping our bodies healthy make us jealous of those who are healthy?

Jealous that they are able to give in to their desire for something impractical without it being a life-threatening mistake?

Most of us with immune deficiencies or other chronic illnesses live in a different world, and we have to deal with it all the time. We have infusions and take medications, and while we can’t feel the difference instantly, making the right choice to maintain our health is gratifying. It may take weeks or even months to notice a change for the better. And, sometimes those changes are so subtle that it takes a good year to realize that a change has taken place. But, thinking back on where we started at the beginning of our treatments and the difficulties faced, isn’t it unbelievable how far so many of us have come? Because of the investment we have made in our health, our quality of life is worth so much more than a designer pair of shoes.

So, what keeps me going — other than the fact that I love living — is knowing that the day will come when I will be walking around healthy with those boots on my feet and a designer bag on my shoulder … all in good time.

Does having this added responsibility for keeping our bodies healthy make us jealous of those who are healthy?

I was diagnosed with CVID and interstitial lung disease in 2004. She is a fashion design student, loves spending time with her fiancé, family and bulldog, Dunkin, and can’t get enough of writing, cake decorating and anything that sparkles!
For generations of American children, summer camp was an annual tradition. Eagerly anticipated or greeted with dread, the image of bus-loads of screaming children heading off to a week or two away from home was simply part of the summer landscape. Yet, while summer camp is no longer as ubiquitous a presence in our culture as it once was, for many families, summer camp still offers timeless benefits to those who attend.

Dr. Shari Delisle, a licensed marriage and family therapist who practices in the San Diego area and specializes in childhood and parenting, says summer camp offers a controlled environment where children can begin to learn to make decisions on their own in a safe setting. “Helping children develop confidence in their own autonomy and competence is the highest parenting duty, however unwelcome a task it may seem,” Delisle explains. “The most fortunate children are those whose parents urged them to become skillful fliers. Sending children off to camp is a perfect half-way measure for practice in flight. The child knows it is a limited period of time, and parents can resume their rooting work when the child returns to the cozy nest. In that most important interlude, a child learns how to master new challenges presented in the camping experience and [his or] her personal confidence is expanded.”

That growth experience at camp, Delisle adds, is even more important for children with chronic medical conditions. “For special-needs children, this camping experience is crucial to the growth of trust — in self and in the world. Like children without these difficulties, they must also receive the gift of personal autonomy and a sense of personal efficacy, however it is modified to fit the special needs of the child.”

Parents of children with immune diseases and other chronic conditions who have attended summer camps and similar weekend retreats echo Delisle’s thoughts, saying their children benefited from the experience. “He came back a changed boy,” Terry Stone of northern Virginia said of her 7-year-old son, Matthew, who attended a camp for hemophiliac children for the first time last summer. “He made a lot of friends and he’s far more independent. Having a kid with a chronic illness, we ‘mamas’ tend to baby them a bit. This kid was pretty sheltered and...
Stacey Henderson sent her two children with ataxia telangiectasia (A-T), an inherited neurodegenerative and immunological disease, to a weeklong camp run by the Muscular Dystrophy Association at Camp Waskowitz in North Bend, Wash.: “The first time they ever went, it was incredible. I think they spent from Sunday to Saturday there, so it [was] almost a full week … [and] both of them cried on the way home; they didn’t want to leave. They wanted the next year to come right away…. They developed a lot of friendships — not just [with] the other campers, but [with] the counselors [with whom] they kept in touch all year long.”

Because Henderson’s children (her daughter passed away a couple years ago) were confined to wheelchairs, finding a camp that could accommodate them was a challenge. Yet, while A-T isn’t muscular dystrophy, the association has adopted this disease to support the children with it, according to Henderson, and invited her children to attend the camp, which they did every year from the age of 7 on. “That time away from the family, it was a great benefit for them because they were able to go somewhere without their family,” she explains. “And they did feel more empowered, I think, that they were able to be away from their family.”

The Format
Like other summer camps, whether in resort towns or run by the Scouts or Girl Guides, camps for special-needs children often have older teenagers serve as counselors to lead the younger campers in their daily activities under the supervision of trained staff. Many of these counselors are former campers themselves, and often they have the same medical condition as the campers. Stone, for instance, says that having older teens and young adult hemophiliacs as volunteers at her son’s camp let him see that his condition was not a roadblock to a happy, active life. As she put it, young children look up to teenagers and young adults in a way that they don’t look up to their own parents. “Matthew had a great comfort level with them,” she explains.

**The growth experience at camp is even more important for children with chronic medical conditions.**

And, of course, special-needs camps also feature the same types of activities as other camps, such as the one Joanne Pease is coordinating — a weekend family camp scheduled next summer in the Yakima, Wash., area, at Camp Prime Time. Theirs will be a three-day weekend camp, from Friday afternoon to Sunday afternoon, and will include crafts and learning classes for the younger kids, outdoor activities, a campfire and a ride on the lake on a barge, among other things.

What is unique to special-needs camps is the onsite medical care and facilities provided, depending on the needs of the children.

**Family Camps, Retreats**
Not all parents are ready to send their children off to camp by themselves. In fact, some parents of children with chronic medical conditions are in as much need of a mutual support system as their children. For these families, family camps or retreats are a good alternative to the traditional summer camp.

Many of the family camps operate like the one Pease is organizing in Yakima, which is in demand from area families whose children have primary immune deficiency (her three grown sons all have it). With campers assigned cabins by family and with shared family meals on Friday and Saturday evenings, the parents can enjoy meeting other parents. Their camp also is open to young adults.

Susan Nadrich of Buffalo, N.Y., took her two daughters to such a family retreat last year in Southern California, and said the experience was life-changing for the entire family. “The Painted Turtle was an amazing place,” Nadrich explains. “I learned about it from reading IG Living magazine. [And, while] it was beyond the deadline when we applied, they said ‘apply anyway.’”

Nadrich and her daughters, 7 and 10, who both have primary immune deficiency, were accepted. “The younger had been having a difficult time. To be able to go to the Painted Turtle and get to know other little children with the same illness and receiving the same
treatment [the same infusions every week] allowed her to not only make new friends, but realize she is not alone. For me as a parent, I too was not able to find anyone else going through what we were going through,” Nadrich says. “To meet other parents was just wonderful. I learned about other methods of treatment, some shortcuts, some ways to make it easier on us. I really hope we can return next fall. My youngest made a best friend — they talk on the phone, and they really understand they’re not alone.”

While the Painted Turtle does offer traditional weeklong camps for the children (and Nadrich admitted her youngest has been bugging her to let her go), she says the weekend retreat seems a better fit: “My thought is that we as a family can benefit more from the family events.”

Yet some parents do use the family retreat as an introduction to the camp programs. Stone said that before sending Matthew off to Camp Holiday Trails in Charlottesville, Va., the family went to a weekend retreat because she was reluctant to let him go to camp at all. “We went to family camp, so they got a chance to get to know the family,” Stone says. “We went in May, and I thought, ‘I can check that off our list; he got to have the camp experience, he slept in a cabin.’ [But, when] we came back, he said, ‘I want to go to camp alone.’”

**Education, as well as Support**

In addition to the growth experience of being away from mom and dad for a week, and the relief of making new friends who are different the same way you are, many children learn important life skills at camps for special-needs children. Stone says that at the hemophiliac camp, the attendees are able to earn a “Golden Stick” award if they learn to self-administer their factor — and that Matthew came home with his the first year. “It’s a little more cool; there’s a little more interest when mom and dad aren’t there,” she adds.

**Family camps or retreats are a good alternative to the traditional summer camp.**

Pease believes that often much of the educational benefit from the family camps and retreats comes not from any experts, but simply from sharing experiences in dealing with a chronic condition. For instance, comparing notes can shed light on new ways of dealing with a situation.

**Finding a Camp**

Over the years, quite a few camps have been started that are geared toward children with chronic medical conditions — including many immunological deficiency diseases and conditions. One way to locate a camp for your child is to ask your local support group, such as other parents you know or a nonprofit group dedicated to your child’s condition.

And many mainstream camps will accept children with primary immune deficiency or other conditions that are under control and require little intervention. If there’s a popular camp in your area, ask the camp director about accommodations for your child.

The late actor Paul Newman founded and funded The Hole in the Wall Gang Camp in Ashford, Conn. Every summer, the camp offers a variety of programs for children with cancer and other serious diseases — at no cost to the family. Learn more at holeinthewallgang.org. The Painted Turtle is another Hole in the Wall camp funded by Paul Newman. It is located near Lancaster, Calif., north of Los Angeles. Find out more at thepaintedturtle.org.

Other camps include Camp Holiday Trails in Charlottesville, Va., which serves special-needs children (campholidaytrails.org); Camp Prime Time in Yakima, Wash., which is also geared toward children with chronic medical conditions (campprimetime.org); and the Immune Deficiency Foundation, which is offering two retreats in 2010, one in Rye Brook, N.Y., from June 25-27, and a second in San Francisco from Aug. 13-15 (primaryimmune.org).
Choosing Mobility Devices

By Kris McFalls

**Canes**

Canes provide a wider base of support and a more stable gait. The most commonly used is a single-point cane that, when placed on the floor, looks like an upside down J.

When possible, a cane should be used on the side of the body opposite the affected leg. For instance, if the left foot is injured, the cane should be held in the right hand. Doing so keeps the body in line with its natural gait motion.

The length of a cane is directly related to the height of the person using it. A cane too long can cause shoulder problems, and one too short can cause poor posture. Improper fit also can cause a loss of balance. When checking the height of a cane, normal walking shoes should be worn. The individual being fitted should stand with normal posture and the arms down and relaxed. To ensure proper height, a second person can turn the cane upside down and place the handle on the floor next to the individual being fitted. The tip of the cane should reach, but not exceed, the crease in the wrist.

**Walkers**

Patients needing more stability than a cane should consider a walker. With greater stability, a patient is more apt to ambulate longer, thus improving endurance and keeping large muscles as strong as possible. As when selecting a cane, normal walking shoes should be worn when being fitted for a walker. While keeping your hands at your sides, make sure the handles of the walker reach the crease in the wrist.

When choosing a walker, close attention should be paid to the wheels. Caster wheels, ones that turn freely when changing directions, are easier to maneuver; however, they are not quite as stable as fixed wheels, which may be needed for weight bearing. Patients needing a little more stability but still wanting the flexibility of caster wheels may want to consider purchasing a walker with hand brakes. Another option is to choose a walker with a seat, which allows the user to take breaks. A walker with a seat is not intended, however, to substitute for a wheelchair.

**Wheelchairs**

Even for those able to ambulate, a wheelchair for longer distances or quicker transportation may be necessary. For short, temporary transportation, a basic collapsible wheelchair may be all that is required. Collapsible wheelchairs are not meant to be a main mode of mobility, however, as the seat does not provide adequate support for long-term use. If a wheelchair is to be the main source of mobility, patients should seek a professional evaluation by a rehabilitation specialist. The patient’s size, physical needs, environment and mode of transportation all need to be carefully assessed. An informative site to visit before meeting with a specialist is [www.healthcare.uiowa.edu/cdd/patients/wcprint.asp](http://www.healthcare.uiowa.edu/cdd/patients/wcprint.asp).

**Quality of Life**

Choosing the right equipment with the proper amount of support is key to optimizing a patient’s quality of life. Utilizing a physical therapist for assistance is advisable. To find one, go to [www.apta.org](http://www.apta.org) and click on the menu option “Find a PT.”
DME Supply Group
DME Supply Group carries a full line of mobility products, including standard wheelchairs and power wheelchairs, a full line of aluminum, lightweight and folding transport chairs, personal mobility scooters, rollators and rollator accessories, walkers and foldaway walkers. Product lines are from top manufacturers such as Lumex, UpRise, Lynx, Everest and others.
www.dmesupplygroup.com; (877) 306-5329

Healthy Mobility Inc.
Healthy Mobility offers a wide selection of aids for mobility, including wheelchairs, walkers, rollators, canes, crutches, scooters and mobility accessories. The company’s top seller in this category is the Invacare Junior Rollator, which features a low seat-to-floor height at 19.5 inches; easy-to-operate, ergonomic hand brakes that lock the rear wheels for security; a lightweight aluminum frame; a removable foam-padded straight backrest; a basket; and a 250-pound weight capacity.
www.health-mobility.com; (877) 435-2203

Medical Department Store
The Medical Department Store carries a complete line of wheelchairs from all the leading manufacturers, such as Invacare, Medline, Sunrise Medical, Drive and more. The company offers free consultation with its wheelchair specialists to ensure the best fit. The website has a wheelchair size and measuring chart, as well as a featured products section.
www.medicaldepartmentstore.com; (866) 586-6154

Nova Ortho-Med
Nova Ortho-Med manufactures mobility and safety products such as canes, walkers and transport chairs. The company started in 1981 as a family owned and operated business. Its newest product is the 348 Ultra Lightweight Transport Chair that features a lightweight aluminum frame, fixed desk arms, easy-to-adjust foot riggings with heel loops, padded upholstery, removable footrests and a seatbelt. It weighs 17 pounds and will accommodate up to 250 pounds.
www.novaortho-med.net; (800) 557-6682

The Scooter Store
Power electric scooters have either three or four wheels and steer using handlebars — much like a bicycle. Electric scooters are designed for outside activities, as they glide smoothly and easily over a variety of surfaces. Some motorized scooters are portable and can be stowed in the trunk of a car. Both three-wheel scooters and four-wheel scooters are available in most models. While most scooters are not reimbursable using the Medicare benefit, The Scooter Store has representatives who can answer questions about using the Medicare benefit for power mobility.
www.thescooterstore.com; (800) 391-7237
For a more comprehensive list of resources, visit the Resources page at www.IGLiving.com.

**General Resources**

**Other Organization Websites**

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

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

**IG Manufacturer Websites**

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

**Disease-State Resources**

### Ataxia Telangiectasia (A-T)

**Websites**

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

### Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

**Websites**

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

**Online Peer Support**

- Barbara’s CIDP/GBS Site: www.geocities.com/HotSprings/Falls/3420

### Evans Syndrome

**Online Peer Support**

- Evans Syndrome Research and Support Group: www.evanssyndrome.net

### Guillain-Barré Syndrome (GBS)

**Websites**

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

**Online Peer Support**

- GBS/CIDP Foundation International Discussion Forums: www.gbs-cidp.org/forums

### Idiopathic Thrombocytopenic Purpura (ITP)

**Websites**

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

### Kawasaki Disease

**Websites**

- American Heart Association (how the disease affects the heart): www.americanheart.org/presenter.jhtml?identifier=4634
Sources

- Kawasaki Disease Foundation: www.kdfoundation.org

Mitochondrial Disease

Websites
- United Mitochondrial Disease Foundation: www.umdf.org

Multifocal Motor Neuropathy (MMN)

Websites
- The Neuromuscular Center at Washington University: www.neuro.wustl.edu/neuromuscular
- The Neuropathy Association: www.neuropathy.org

Multiple Sclerosis (MS)

Websites
- All About Multiple Sclerosis: www.mult-sclerosis.org/index.html
- Multiple Sclerosis Association of America: www.msaan.com
- Multiple Sclerosis Foundation: www.msfacts.org
- National Multiple Sclerosis Society: www.nationalmssociety.org

Online Peer Support
- Friends with MS: www.FriendsWithMS.com
- MSWorld’s Chat and Message Board: www.msworld.org

Myasthenia Gravis (MG)

Websites and Chat Rooms
- Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org

Online Peer Support
- Autoimmune Information Network Inc.: www.aininc.org

Myositis

Websites
- 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
- International Myositis Assessment and Clinical Studies Group: https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main
- The Cure JM Foundation www.curejm.com (760) 487-1079

Online Peer Support
- Myositis Association Community Forum: www.myositis.org
- Myositis Support Group: www.myositisupportgroup.org
- Myositis Support Group – UK: www.myositis.org.uk

Pemphigus and Pemphigoid

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

Peripheral Neuropathy (PN)

Websites
- 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

Online Peer Support
- Neuropathy Action Foundation: www.neuropathyaction.org

Online Peer Support
- Calgary Neuropathy Support Group: www.calgarynpers.org

Primary Immune Deficiency Disease (PIDD)

Websites
- The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. (800) 296-4433

- The Jeffrey Modell Foundation, www.info4pi.org, is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency. (212) 819-0200

Online Peer Support
- 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 "American Academy of Allergy, Asthma & Immunology: www.aaaai.org
- International Patient Organization for Primary Immunodeficiencies (IPOPI): www.ipopi.org
- Michigan Immunodeficiency Foundation: www.midf.org
• National Institute of Child Health and Human Development (NICHD) (Click on “Health Information and Media” tab and search for “primary immunodeficiency”: www.nichd.nih.gov
• New England Primary Immunodeficiency Network: www.nepin.org
• Rainbow Allergy-Immunology: www.rainbowbabies.org/immunology
• Team Hope (for families and patients in New England): www.teamhope.info

Online Peer Support
• IDF Common Ground: www{idfcommonground.org
• IDF Discussion Forum: my.primaryimmune.org/forum
• IDF Friends: www{idffriends.org
• Jeffrey Modell Foundation Message Board: www.info4pi.org
• Rhode Island peer group: http://health.groups.yahoo.com/group/RhodeIslandPIDD

Scleroderma

Websites
• Scleroderma Center: http://scleroderma.jhmi.edu
• Scleroderma Foundation: www.scleroderm.org
• Scleroderma Research Foundation: www.srfcure.org

Online Peer Support
• CureZone.com: curezone.com/forums/f.asp?f=404
• International Scleroderma Network: www.sclero.org/supportforums/a-to-z.html

Stiff-Person Syndrome (SPS)

Websites
• American Autoimmune Related Diseases Association Inc.: www.aarda.org
• Autoimmune Information Network Inc.: www.aininc.org
• Living with Stiff Person Syndrome (personal account): www.livingwithspss.com

Other Resources

Education and Disability Resources
• Americans with Disabilities Act of 1990: www.ada.gov
  Provides protection for people with disabilities from certain types of discrimination, and requires employers to provide some accommodations of the disability.


• DisabilityInfo.gov: www.disabilityinfo.gov
  U.S. Federal government’s disability-related information and resources.

• Individuals with Disabilities Education Improvement Act of 2004: http://idea.ed.gov/explore/home

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

• Social Security: www.ssa.gov/disability

• U.S. Department of Education Website: www.ed.gov
  This federal government website offers a parents section titled “My Child’s Special Needs.”

  Spells out your rights under Section 504 of the Rehabilitation Act.

Medical Research Studies
• ClinicalTrials.com: www.clinicaltrials.com
  This site has a registration form to request that you be notified about recruitment for future studies.

• ClinicalTrials.gov: www.clinicaltrials.gov
  A registry of federally and privately supported clinical trials conducted in the United States and around the world.

Food Allergies
• Allergic Disorders: Promoting Best Practice: www.aaaai.org
• American Partnership for Eosinophilic Disorders: www.apfed.org
• Food Allergy and Anaphylaxis Network: www.foodallergy.org
• World Allergy Organization: www.worldallergy.org

Product Information
• Influenza and the influenza vaccine: www.cdc.gov/flu or call (800) CDC-INFO: (800) 232-4636
• IVIG Carimune NF: www.carimune.com
• IVIG Flebogamma: www.grifolsusa.com/pdfs/flebo_14Jun05.pdf
• IVIG Gammagard Liquid: www.gammagardliquid.com
• IVIG Gammagard S/D: www.immunedisease.com
• IVIG Gamunex: www.gamunex.com
• IVIG Octagam: www.octapharma.com
• IVIG Privigen: www.privigen.com
• SCIG (subcutaneous immune globulin) Vivaglobin: www.vivaglobin.com

Pump and Infusion Sets Websites
• EMED Corporation: www.safetymedicalproducts.com
• Graseby Marcal Medical: www.marcalmedical.com
• Intra Pump Infusion Systems: www.intrapump.com
• Micrel Medical Devices: www.micrelmed.com
• Norfolk Medical: www.norfolkm edical.com
• Repro Med Systems, Inc: www.rmsmedicalproducts.com
• Smith Medical: www.smiths-medical.com/brands/cadd

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