

## Electronic Health Records

*The Future of Coordinated Care*

**Probiotics to Ease GI Distress**

**Is Your Infusion Nurse Qualified?**

IG Insurance:  
Protecting Against  
Policy Change

Clinical Drug Trials:  
Are They for You?

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### About *IG Living*

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# The Truth About IG Access



**RECENTLY, THE AVAILABILITY** of immune globulin (IG) was of critical concern to patients who were told there was not enough product, causing many to switch to alternate IG products or even forgo treatment. But while, historically, IG has had periods of short supply, with one period just ending, today IG is in ample supply, and in the majority of cases, Medicare and private insurance companies are reimbursing the cost of the product. What does this mean for you, our readers? You should have no trouble securing the IG product you need.

Understanding why there was a short supply of IG will arm you with the knowledge of what will likely happen again and what you can do to help. Basically, the supply and demand of IG is continually fluctuating. When demand is higher than supply, IG is in what is known as a “short” market, which typically means increased prices for the product. When supply is higher than demand, IG is in a “long” market, which typically means decreased prices.

The cycle from a short to a long market and back again is the result of current and predicted demand. Demand for IG has steadily increased over the years. This is due to an increasing number of patients being treated with IG due to doctors prescribing it for off-indicated uses, as well as expanded research that shows IG is effective in treating even more conditions. And, as demand increases, manufacturers increase production — sometimes too much too quickly. When this happens, the spike in production is temporarily greater than demand, creating a long market, so manufacturers necessarily cut back. But, it’s hard to predict how much to cut back, mostly because of plasma availability and the amount of time (seven to nine months) it takes to make IG through the fractionation process. When production is cut back too much, there is a shortage of IG (a short market).

As prices rise in a short market, patients

often have trouble accessing the IG product they need.

This is primarily a result of the current reimbursement model. Medicare reimburses IG based on the published average sale price (ASP), which is determined by the drug pricing data submitted by manufacturers from the previous two quarters. Although the ASP rate changes each quarter, it lags six months behind the current market pricing, leaving health-care providers paying more for IG than they are reimbursed.

Inadequate reimbursement often limits patient choice, with some clinics offering patients only one or two of the least costly IG products. In the private insurance market, companies have been restricting access to IG. And, many companies are restructuring their IVIG policies, requiring step therapy that mandates patients first fail other treatments before being granted access to IG. What’s worse is that insurance companies are following Medicare’s lead, and also are cutting reimbursement rates.

So, what can patients and healthcare providers do? Stay educated about the IG market, and get involved to help fix reimbursement rates. Activist patients can serve as catalysts for other organizations, such as the Alliance for Plasma Therapies ([www.plasmaalliance.org](http://www.plasmaalliance.org)), patient associations, and FFF Enterprises Inc., publisher of *IG Living* magazine, that are working to do what is right for patients.

While IG is in ample supply right now and you should have access to the product you need, a short market will return at some point. Let’s all do our part to change the reimbursement model so that whether it’s a short or long market, you will have fair access to your IG product of choice. ■

Ronale Tucker Rhodes, MS, Editor

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IMMUNE GLOBULIN COMMUNITY

*Our mission is to support the IG community through education, communication and advocacy*

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## Readers Write

### Shedding Light on Autoimmunity and PIDD



Dear Editor,

I want to thank Lauren Gerstmann and *IG Living* for the article "Immune Deficiency and Autoimmune Disease: A Complicated Relationship" [June-July 2009, p. 28]. I was very excited to finally see something in the literature linking these two seemingly opposite disease categories. My son had accumulated a list of eight different autoimmune disease diagnoses before his primary immunodeficiency (PIDD) was diagnosed in 2004. For him, these autoimmune processes were more debilitating than his chronic infections more commonly associated with PIDD. I believe it is important for any person with chronic autoimmune disease and infections to ask their doctor about the possibility of PIDD; we wish we had known to ask about it sooner. I applaud Lauren for raising awareness about autoimmune disease as an important, but often overlooked symptom of PIDD.

— Amy, Illinois

### Community Story Benefits Reader

I ran across your magazine at my neurologist's office and loved it so much, I asked him if I could keep it. After reading all of it, I saw that the subscriptions are free. I wanted to share with you how much I love your magazine! I have fibromyalgia, and my daughter has an immunoglobulin deficiency. I signed both of us up for a subscription, as she is out on her own now. Even I, with fibromyalgia, benefit from the amazing and wonderful testimonies that are shared. I just read "The Child Within" by Ever Fecske in the April-May 2009 issue and could only think "wow!" and "thank you!"

— Karrie, Washington

Whoo hoo for chronic inflammatory demyelinating polyneuropathy info! The fact that a person ["Let's Talk!" April-May 2009, p. 28] got diagnosed in less than six months is amazing! I thought I was a record breaker at

just a week over a year, but it took three neurologists to get there. CIDP is getting diagnosed so much faster, and treatment is key to keeping damages at bay. Had my first neurologist diagnosed it at first, I wouldn't be on year five of MIG... We all have to know what is happening to us: how, when and why. Your magazine is doing that very well. ■

— Joan, Virginia

Your feedback, opinions, suggestions and anything else you'd like to share are important! Email us at [editor@IGLiving.com](mailto:editor@IGLiving.com) or visit [www.IGLiving.com](http://www.IGLiving.com) and go to the Contact Us page to send your comments.

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## Contributing Experts



**KRIS MCFALLS**

*Patient Advocate, IG Living magazine*

### Protecting Against IG Insurance Policy Change

"Most patients don't know an IG policy exists until they experience a denial of coverage."



**RACHEL MORTON**

*Editor, Emma magazine*

### Extraordinary Measures for an Ordinary Life

"Lilly has mitochondrial disease, a rare and often disabling illness that can make summoning the energy to do something like stand and sing nearly impossible."



**AMY SCANLIN, MS**

*Freelance Writer*

### Coordinated Care with Electronic Health Records

"One of the major benefits of EHRs is the ability of patients to take an active role in their care."

## Did You Know?

### Healthcare

## Igi V. Play Kit Introduced for Kids



In an effort to help children who undergo intravenous immune globulin therapy deal with the treatment, Baxter Healthcare Corp. is offering the Igi V. (pronounced Ig-e-vee) Therapeutic Play Kit free. The brainchild of Dayna and Brian Fladhammer, parents of three children with primary immune disease, with the help of their child life specialist,

Adina Bodolay, the kit was designed to help child life specialists and caregivers connect with children to communicate about medical issues and environments. Specifically, the kit helps children learn strategies to cope with the medical environment; gain a better understanding of medical procedures, including IV starts, CT scans and blood draws; and express thoughts and feelings about living with primary immunodeficiency.

Included in the kit is the Igi V. doll, a blue bear with limbs that have joints and a belly button to help identify locations on its body, an Igi V. Infusion Toolkit with real medical supplies for children to practice infusion with the doll, a booklet titled "A Guide to Therapeutic Play" for parents and other caregivers, an Igi V. Is Just Like Me booklet, and an Igi V.'s Medical Records booklet. The kit can be ordered at [immunedisease.com/patients-and-families/help-and-support/therapeutic-play](http://immunedisease.com/patients-and-families/help-and-support/therapeutic-play). ■

### Legislation

## Bill Introduced for Autoimmune Disease

On April 23, House bill H.R. 2084, Prevention, Awareness and Research of Autoimmune Diseases (PARAid) was introduced by Rep. Patrick J. Kennedy, D-R.I., and co-sponsored by Rep. Cliff Steans, R-Fla., and Rep. James P. McGovern, D-Mass. The bill proposes to infuse more than \$43 million in new funding for research into the environmental triggers of autoimmune diseases, grants to increase awareness of autoimmune diseases, grants for education on the relationship between autoimmune diseases and mental illness, loan repayment for physician research, and research and database on biomarkers of autoimmune disease. The National Institutes of Health estimates that 23.5 million Americans suffer from an autoimmune disease, and the prevalence is on the rise. ■

### Legislation

## German Initiative Targets Immune Defects

Doctors in Germany have founded an initiative, known as the Find ID network, aimed at raising awareness among health professionals about immune system defects in children. The hope is that greater awareness will lead to cases being detected earlier so children can receive therapies faster. The project will also help doctors avoid making false diagnoses and will train pediatricians, ear, nose and throat doctors and general practitioners to identify suspected cases and transfer them to specialist care. ■

### Research

## IG Therapy for Post-Lyme Disease

Intravenous immunoglobulin (IVIG) therapy may improve neuropathic symptoms in patients with post-treatment Lyme syndrome (lingering symptoms of Lyme disease), according to a report by researchers at the 61st Annual Meeting of the American Academy of Neurology. In a study of 30 patients who complained of neuropathic pain, 22 had a history of Lyme disease and eight had received the Lymerix vaccine (which causes similar neuropathic symptoms). All patients were treated with IVIG 2g/kg per month for at least six months, and all showed

neurological improvement. "The diagnosis of chronic Lyme disease is not widely accepted, yet these patients have symptoms and nerve biopsies that respond to IVIG treatment, legitimizing their complaints," said presenter Amiram Katz, MD. ■

### Did You Know?

*Xylitol-flavored chewing gum has been found to reduce the incidence of middle-ear infections in children by 40 percent.*

## Did You Know?

### Research

## Neurological Disease Begins in Prime Years

A new national poll conducted by The Neuropathy Association finds that the majority of respondents had their neurological disease begin during their prime adult years, with 82 percent experiencing neuropathy's onset between the ages of 30 and 69.

The survey of 1,300 patients asked about the age when their neuropathy began, which showed that 3 percent had their illness start in their 20s, 27 percent had their illness start in their 30s and 40s, and 55 percent had their illness start in their 50s and 60s. The survey also asked 1,000 patients to identify their specific type of neuropathy. Fifty-two percent responded that their neuropathy was idiopathic, meaning no known cause, followed by diabetic (15 percent) and autoimmune related (12 percent).

Peripheral neuropathy (nerve damage) affected more than 20 million



Americans, making it one of the most common chronic diseases in the U.S. Neuropathy's symptoms include weakness, numbness, tingling and pain, especially in the hands and feet. ■

### Medicine

## Simponi Approved by FDA to Treat RA

The U.S. Food and Drug Administration has approved the drug Simponi (golimumab) to treat three forms of arthritis that occur when the body's immune system attacks the joints. Administered once a month, the injected drug was sanctioned to treat moderate to severe rheumatoid arthritis, active psoriatic arthritis and active ankylosing spondylitis. Simponi is among a class of drugs that target

tumor necrosis factor-alpha (TNF-alpha). When overproduced, this protein can cause inflammation and damage to bones, cartilage and tissue. Simponi's label will include a warning that users face an increased risk of tuberculosis and invasive fungal infections, according to the FDA. Common side effects of the drug include upper respiratory tract infection, sore throat and nasal congestion. ■

### Did You Know?

*Bicyclist Chris Paradysz recently raised \$40,000 to fund research on systemic lupus erythematosus by riding 415 miles to break the famous Valley Preferred Cycling 24-hour track record. That is enough to pay for at least a one-year research fellowship.*

### Disease

## Autism Linked to Autoimmune Disease

A new study reveals that children of mothers who have autoimmune diseases such as type 1 diabetes, rheumatoid arthritis and celiac disease have up to a three times greater risk for autism. Although the association between autism and a maternal history of type 1 diabetes and rheumatoid arthritis had been found in earlier research, the new study published in the July 6 online edition of *Pediatrics* is the first to find a link between autism and celiac disease.

Researchers collected data on 3,325 Danish children born between 1993 and 2004 diagnosed with autism spectrum disorder, including 1,089 diagnosed with infantile autism. Children whose mothers had

autoimmune disease were at a higher risk of developing autism spectrum disorder than children of mothers who did not have these conditions. In addition, the risk of infantile autism was increased in children with a family history of type 1 diabetes.

"This finding is on the pathway of finding the cause of autism," said researcher William W. Eaton, chairman of the Department of Mental Health at the Bloomberg School of Public Health at Johns Hopkins University. However, he noted that individuals affected with these diseases should not worry, as the large majority of people affected by an autoimmune disease do not have children with autism. ■

## Research

# Study Redefines CIDP Diagnosis



New research conducted at the Jefferson Hospital for Neuroscience may redefine how chronic inflammatory demyelinating polyneuropathy (CIDP) is diagnosed. The study, available in the June edition of the *Journal of Clinical Neuromuscular Disease*, involved 26 CIDP patients and a control group of 21 patients, nine ALS (Lou Gehrig's disease) patients and 12 diabetic neuropathy patients. Researchers looked at the number of

demyelinating features that are needed to differentiate between CIDP, ALS and diabetic neuropathy, and found that a minimum number of three demyelinating features can be used to positively identify CIDP in a patient. "This is a clinically significant finding that may help doctors screen potential CIDP patients," said lead researcher Eduardo De Sousa, MD. "In determining the number of demyelinating findings needed to define CIDP, doctors may be able to make a diagnosis sooner, allowing for a targeted treatment to begin quicker, preventing further disability."

CIDP, which affects approximately 50,000 people in the U.S., is a neurological disorder characterized by progressive weakness and impaired sensory function in the legs and arms. Currently, to make a CIDP diagnosis, patients undergo nerve conduction studies to determine the number and severity of abnormalities on electrodiagnostic tests. Patients with a specific pattern and number of abnormalities are determined to have CIDP. ■

## Supplier

# CSL Behring Applies for SCIG License

CSL Behring has applied to the U.S. Food and Drug Administration to market its 20 percent liquid formulation Immune Globulin Subcutaneous (IgSc) in the U.S. for weekly replacement therapy in patients with primary immunodeficiencies. The ready-to-use, high-concentration subcutaneous immunoglobulin (SCIG) is stabilized with L-proline, a naturally occurring amino acid and can be stored at room temperature. CSL has completed four clinical trials in primary immunodeficiencies in the last four years. If approved, it will be the second treatment option for patients who prefer at-home self-administration of IG therapy. ■

## Did You Know?

*One in five U.S. workers is uninsured today, a statistically significant increase from fewer than one in seven during the mid-1990s.*

**— Robert Wood Johnson Foundation study**

## Research

# Herb May Curb Autoimmune Disease

In a recent study, a compound derived from hydrangea root halted the progression of an autoimmune disorder in laboratory mice and human cells.



The compound, halofuginone, shows promise because it slowed progression of the disease without suppressing normal immune system functioning.

In the study, researchers gave halofuginone to mice with experimental autoimmune encephalitis, an artificially induced immune disease that resembles multiple sclerosis in humans. They found that low doses of halofuginone inhibited the devel-

opment of Th17 cells (those implicated in a variety of autoimmune disorders) in mice, but did not alter other kinds of T cells important for normal immune function.

Halofuginone is one of the 50 fundamental herbs of traditional Chinese medicine, and has been used as an anti-malarial agent. It is also used to treat scleroderma, an autoimmune disease of connective tissue. ■

## Did You Know?

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### Foundation

## IDF Launches Social Portal

The Immune Deficiency Foundation has launched a new social portal, an online community to learn and share about primary immunodeficiency diseases. The portal includes four separate sites. IDF Friends ([my.primaryimmune.org](http://my.primaryimmune.org)) allows patients to find and befriend others with whom they share common interests, create “user

group” communities around a particular interest, participate in ongoing, “threaded” conversations on a variety of topics and share stories in words, pictures or video. IDF Arcade ([www.primaryimmune.org/flashgames/idf\\_flashgames.asp](http://www.primaryimmune.org/flashgames/idf_flashgames.asp)) features a variety of games designed for children ages 4 to 12 to learn about the immune

system. IDF Common Ground ([www.idfcommonground.org](http://www.idfcommonground.org)) is a community for teens and young adults with primary immunodeficiencies. And, IDF Reel Stories ([www.youtube.com/idfreelstories](http://www.youtube.com/idfreelstories)) allows individuals to create and review videos that relate to life experiences with primary immunodeficiencies. ■

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### Disease

## Two New Drugs May Fight MS

The relapse rate in people with multiple sclerosis (MS) was cut in half with the use of two new oral drugs. If approved by the U.S. Food and Drug Administration, the drugs, cladribine and fingolimod, would be the first treatments for MS that don't involve

regular injections or infusions.

In one study, 80 percent of MS patients who took the chemotherapy drug cladribine were relapse-free for two years versus 61 percent of those given a placebo. In a second study, 80 percent to 84 percent of MS patients taking the

immune-suppressing drug fingolimod were relapse-free after one year of daily treatment, compared with 67 percent of those taking the standard injectable MS drug, Avonex. Both studies were presented at the annual meeting of the American Academy of Neurology. ■

# Protecting Against IG Insurance Policy Change

By Kris McFalls

**A PATIENT WITH** dermatomyositis was recently denied by her insurance company for immune globulin (IG) treatment, despite being treated with IG for the past six years. This patient's case isn't isolated according to Jennifer Jaff, executive director of Advocacy for Patients With Chronic Illness, who heard from other patients with the same insurance who were also denied coverage. Further investigation revealed that this particular insurance company had conducted a recent review of its IG policy and elected to make some changes.

Jaff explains that "drug issues are one of the things that are always subject to change. Most terms of an insurance policy can't be changed until the end of the policy term. But when it comes to drug issues — prior authorization requirements, drug tiers, formularies, approved uses — insurance companies can change the contract at will, unless state law says otherwise and the patient is not in a self-funded plan. For example, in Connecticut, there is a statute that says an insurer can't eliminate coverage of a drug in the middle of a policy term. But that differs from state to state."

## Understanding the IG Policy

Most patients don't know an IG policy exists until they experience a denial of coverage. In addition, many patients don't know they need to read the policy before their case is up for a review and reauthorization, much less how to access the policy. It's often true that patients expect their physicians to monitor their policy's

requirements to get needed treatment, yet it is unreasonable to expect physicians to stay current with the contents of every insurance policy.

The reality is that patients are part of a team and, as such, bear some of the responsibility for getting IG infusions approved by their insurance company. For their part, patients need to educate themselves and keep documentation. They should know when their policy's IG authorization expires. And, they should be sure to see their doctor a month or

*Most patients don't know an IG policy exists until they experience a denial of coverage.*

two prior to the expiration of the authorization to start the process of filing a reauthorization request. Some insurance companies allow a reauthorization request to be filed within only 30 days of the expiration. So, it's important that patients be sure to check their policy in plenty of time before a request is filed.

## Protecting Against Policy Change

Many policies or coverage determinations can now be accessed either by the patient or doctor via the Internet.



However, finding the policies can prove difficult even for experienced Internet users.

Those not familiar with navigating the Internet should call the customer service line listed on their insurance card and request a copy of the IVIG policy or coverage determination. Their diagnosis, the ICD-9 code (diagnostic code) and the brand name of their IG product will need to be provided — all of which can be obtained from their doctor. To document the call, a log of whom they talk to, the date and time, as well as notes about the conversation should be kept.

## Knowledge Is Power

It comes down to this old adage: Forewarned is forearmed. To be an effective team member, patients need to stay focused and not give up. Knowledge is power. The more they know ahead of time, the better they can prepare for changes and the less likely they will experience a break in treatments because of insurance snafus. For more information or help regarding IVIG policies, patients can write to us at [www.igliving.com](http://www.igliving.com) by clicking on Contact Us, or they can call (888) 469-9720 for assistance. ■

**KRIS MCFALLS** is IG Living's full-time patient advocate.

# Clinical Drug Trials: Are They for You?

Individuals interested in participating in drug trials should be sure to understand their purpose and benefit for their own health, as well as the health of future generations.

By Ronale Tucker Rhodes, MS



**W**hile most people will never have to decide whether to participate in a clinical drug trial, this decision can be commonplace for individuals diagnosed with a disease. How their participation comes about can vary. Either a physician, researcher or drug company asks them to participate, or individuals themselves seek out trials in an effort to find answers to their treatment.

Participation in clinical drug trials can offer benefits to all parties involved: individuals seeking treatment, drug companies striving to develop the most effective diagnoses and medicines, and researchers looking to test the effectiveness and dosages of medicines by themselves or in combination for certain populations. And while apparently healthy individuals

may not often participate in drug trials, they can play an important role in them — specifically in the disease diagnosis process — which can be especially important for those with autoimmune and primary immune diseases, many of whom search for answers to their medical problems for years before being diagnosed.

### What Is a Clinical Drug Trial?

Thousands of clinical drug trials are conducted every year across the U.S. and abroad. The purpose of clinical trials is to study drug reactions in people to answer specific health questions. The different types of clinical trials include prevention options; new treatments or new ways to use existing treatments; new screening and diagnostic techniques; and options for

improving the quality of life for people who have serious medical conditions. Typically, trials compare a new product or therapy to another to see if it works as well or better to treat or prevent a disease or condition.

Because clinical trials are sponsored by various entities, such as physicians or other healthcare providers, pharmaceutical companies and federal agencies, participation details, such as location, frequency, duration, demographics, etc., will vary. It is up to the sponsoring organization to determine where participants will need to go and how often, but in most cases, participants receive treatments at universities, medical centers, clinics, doctors' offices, hospitals and federally and industry-funded research sites.

All clinical trials are regulated according to strict guidelines set by the U.S. Food and Drug Administration (FDA). The FDA has established five phases of clinical trials, with Phase 0 being the newest designation. Phase 0 is designed to determine if a drug behaves in humans the same way it did in preclinical testing, and it typically involves a small number of subjects. Phase I, the first major testing stage, monitors a small group of subjects in in-patient clinics to determine a drug's toxicity, side effects, interaction with the body and proper dosage levels. Phase II commences after a drug's safety is established, and further studies the drug's effectiveness, but on a larger

group of people. Phase III trials, considered the last step on a drug's way from the lab to the pharmacy, test large groups of subjects to compare the drug against the current standard (existing) treatment for a particular condition. Phase IV trials take place after the drug has been approved and released, and are used to further understand the drug, such as how it interacts with other medications and what its long-term effects may be.

### **What Are the Possible Risks and Benefits to Patients?**

FDA guidelines for clinical drug trials are intended to protect patients from unreasonable risks. Prior to participation, researchers must provide study subjects with complete and accurate information about what to expect during the trial, after which an "informed consent" document must be signed by participants. All participants are free to leave a trial at any time. This is not to say, however, that clinical trials are not without risks. The most common risks include unexpected and serious side effects, an additional commitment burden on the participant, and even the possibility that the treatment will be ineffective.

Oftentimes, the benefits outweigh the risks. Participating in clinical drug trials allows eligible participants to get actively involved in their healthcare, and offers many other advantages. In some instances, trials enable participants to receive medicines free of charge. In most trials of immune globulin products, patients receive free medication for the duration of the study, which typically lasts between 12 and 18 months. In addition, they are provided access to expert medical

care for their condition. In some trials, participants are compensated for either their time and/or their expenses. Of course, the greatest benefit of all is treatment that works. In this instance, it's important that individuals understand that not only are they personally benefiting from participation, but they are helping future patients by contributing to medical research.

### **How Do Patients Locate the Right Trial?**

While greater awareness has been raised concerning clinical drug trials, companies and researchers are finding that getting people to participate in

*FDA guidelines  
for clinical drug  
trials are intended  
to protect  
patients from  
unreasonable risks.*

these trials is becoming more challenging than ever before. This is mainly due to an increasing number of clinical trials, requiring more patients.<sup>3</sup> To compete, researchers have resorted to nontraditional tactics, such as newspaper and radio advertising, email postings and even Internet-based social networks that attract people who share a particular disease.

Patients seeking out a clinical trial pertaining to their disease can look to a few sources. The most complete listing of clinical trials can be found at [clinicaltrials.gov](http://clinicaltrials.gov), an interactive online data-

base managed by the National Library of Medicine for locating federally and privately supported clinical trials for a wide range of diseases and conditions. As of this writing, there were 111 posted clinical trials for intravenous immune globulin (IVIG) and five posted trials for subcutaneous immune globulin (SCIG). The site is updated regularly and offers information on each trial's purpose, who is eligible to participate, locations and phone numbers to call for additional information.

Patients should also consider consulting with their physicians to see if they can recommend a clinical trial. And, they can also visit their local medical facilities, which will oftentimes list drug trials being conducted by specialty physicians.

### **Physician Support**

With the growing number of clinical drug trials being conducted in the world today, patients have more options than ever to play a role in their healthcare treatment. The key is to carefully evaluate whether a trial may be beneficial for them, and remember that it is a trial, not a guarantee, that their participation will provide the answers that will help them, as well as others. ■

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# Coordinated Care with Electronic Health Records

Implementation of an electronic health record system will create an interoperable healthcare system for more efficient patient care.

By Amy Scanlin, MS

**H**ealthcare is entering a new era — one that will be especially important for individuals with autoimmune and immune deficiency diseases. This new health information technology (HiTech) era will make health information interoperable, allowing physicians, labs and insurance companies to exchange data and communicate quickly and efficiently to provide the best possible care for patients — all made possible with electronic health records (EHRs). Whether the patient is between specialists for a chronic disease, having routine exams or tests, or even a victim of a disaster such as Hurricane Katrina, EHRs will enable a wider breadth and depth of care.

EHRs store patient information, protect patient privacy and allow for the retrieval and proper dissemination of information, including insurance. As more healthcare entities (ambulatory, emergency, hospital-based) roll out their EHR programs, EHRs will become an integral part of healthcare for every American. The government is going to great lengths to ensure this initiative is successful on all levels, and as we get closer to the deadline of full EHR implementation, things are changing rapidly.

## EHR Beginnings

On April 27, 2004, President Bush signed Executive Order 13335 with the goal of developing and implementing a nationwide infrastructure for health information technology that would improve the quality of healthcare. He also established the Office of the National Coordinator (ONC) of Health Information Technology within the U.S. Department of Health and Human Services to ensure a number of benchmarks are met:

1. Patient's health information is secure, protected and available to the patient.
2. Appropriate information is available to guide medical decisions at the time and place of care.
3. Healthcare quality is improved while reducing healthcare costs resulting from inefficiency, medical errors and inappropriate care.
4. Information dissemination between hospitals, laboratories and physician offices is improved.

Bush's goal was to provide the majority of Americans access to their EHRs by 2014. And, while President Obama's February 2009 joint address to Congress echoed the initiative to move forward with EHRs, he wants to speed up the timeline. Obama's American Recovery and



Reinvestment Act of 2009 (ARRA) gives priority to EHRs as part of his overall healthcare reform, and he is providing stimulus money to healthcare providers that initiate and can show “meaningful use” of electronic systems.

Starting in 2011, financial incentives will encourage healthcare providers to convert to electronic systems earlier than 2014.<sup>1</sup> As 2014 nears, the incentives will become smaller, and by 2014, financial penalties will be imposed on healthcare providers that have not switched to electronic health information systems. “The expectation is that adoption will increase dramatically when these incentives become available,” says Deven McGraw, director for the health privacy project at the Center for Democracy and Technology.

According to an article in *Healthcare IT News*, “More than two-thirds of physicians in the country will respond to the incentives offered by the HITECH (Health Information Technology for Economic and Clinical Health) portion of the American Recovery and Reinvestment Act because it represents a ‘significant’ incentive. However, participation is likely to be skewed toward practices with more than three physicians.” Therefore, to achieve the greatest results, it is suggested that the government provide smaller practices with technical and financial assistance.<sup>2</sup>

### Where Are We Now?

The current EHR adoption rate is roughly 10 percent, making 2014 a very ambitious timeline to get healthcare providers on board. Large organizations such as Kaiser Permanente and the U.S. Veterans Administration are currently leading the way, but smaller practices are slower to go electronic. One reason is that switching to an electronic system is costly, which is why the government is offering financial incentives. In addition, many physicians are comfortable with the way their offices currently operate and are uncomfortable with changing computer systems and the associated issues such as computer literacy, security, etc. There is also a lot of confusion about the best way to go electronic.

To receive stimulus money, not only must the healthcare provider use a “certified” EHR product, it must be doing so in a “meaningful” way. The term “meaningful” is at the center of debate as planners — from Congress to HiTech companies to physicians — come together to determine specifically what “meaningful use” means. It is anticipated that electronic prescribing, laboratory reporting,

clinical summaries for care coordination and quality data will be covered in the definition.<sup>3</sup>

Therefore, for companies that are ready to go electronic, it is recommended that the contracts with EHR providers include a provision that states the system will work when the definition of “meaningful use” has been determined by the Secretary of Health and Human Services.

The requirement for the use of a “certified EHR” also remains to be defined. Currently, EHR products are certified by the Certification Commission for Healthcare Information Technology (CCHIT). On May 29, 2009, CCHIT released its “Concise Guide to 2009 CCHIT Criteria

*Starting in 2011, financial incentives will encourage healthcare providers to convert to electronic systems earlier than 2014.*

for ARRA-qualified EHRs,” and it anticipates final criteria to be in place in August after the proposed criteria are examined by the ONC to ensure compliance with ARRA stimulus guidelines. Each year, the certification criteria are intended to improve upon the previous year’s requirements, as technology gets more advanced and improvements are needed in the system. According to the ONC, “There is a lot of work that needs to be done. Numerous efforts are under way to address critical issues and launch grant and incentive programs to spur the adoption of EHRs. These programs will be announced in the next several months.”

### EHRs in Action

The Department of Veterans Affairs (VA) has been using EHRs for over a decade and has won awards from Harvard’s Kennedy School of Government and praise from journals such as the *New England Journal of Medicine* for one of the most comprehensive and sophisticated usage of EHRs in the nation. The initiatives VA is using are similar to those patients can expect to see as healthcare providers adopt the EHR system.

When doctors view a patient's records, they instantly see active health concerns, allergies, medications, recent lab results, etc. The system also alerts doctors, before an order is placed, to any potential problems, and offers benefits such as e-scribing (an automated prescription drug process) to prevent misread prescription orders.

VA's EHR system uses VistA Imaging, which allows doctors to see X-rays, pathology slides, photos taken during endoscopies, surgeries, eye exams, etc., including those taken at other VA locations. The system also uses bar-coded

adult children helping aging parents or for veterans who receive some of their care from non-VA sources. "We have been fortunate," says Graham, "that our vets have embraced the electronic health record and have come to expect it. It allows for the continuity of care wherever the patient is in the country. We see big changes as [the adoption of EHRs increases and] we are able to connect more with the private sector. Our goal is to be here to support the president's initiative."

### Patients' Role in EHRs

One of the major benefits of EHRs is the ability of patients to take an active role in their care. When checking in for an appointment, patients are by law given a "Notice of Information Practices" to sign. Patients have the right and should be provided access to view their health information in a readable format (however, they may be charged a copy fee). Information should be checked to be certain it is up to date and accurate. Patients may dispute the accuracy of their records and either have the information changed or have the dispute documented in the records if the request for change is denied. This is an important step, because incorrect information replicated through the course of care can have serious consequences. Potentially, incorrect information could be anything from administrative errors to medical identity theft, so the opportunity and responsibility for review should be taken seriously. Patients should also understand what health information is in their EHR, how it is being used and who has access to it.

A major initiative for the government is to educate people about HITech and to communicate with everyone involved. According to Meryt McGindley, acting communications director for the National eHealth Collaborative, "We want people to know why this is important, how the healthcare system will go about making the switch and how we will overcome barriers to implementation. We have choices in this country as to where we get our healthcare, and healthcare reform is a major topic of discussion. A lot of people think doctors are already networked and that we are a lot further along than we are. So ask questions when you are choosing a doctor, choosing a specialist, choosing a hospital. Will [the healthcare providers] all be able to communicate?"

### Security and Privacy Laws

Patients' health information should be shared only under necessary circumstances that enable providers to

*Patients' health information should be shared only under necessary circumstances that enable providers to accomplish their specific goals for patients.*

medication administration that scans the prescription and the hospitalized patient's wristband to ensure accuracy. VA states that medication errors have been reduced by two-thirds with this technology.

Patients can also create a Personal Health Record (PHR) using VA's My HealtheVet, at [www.myhealth.va.gov](http://www.myhealth.va.gov), and VA is gradually allowing online access to the patient's EHR as part of this PHR (patients can request their full records at any time). This is highly beneficial to both doctors and patients, because patients are able to take a more active role in their healthcare. "We use the EHRs as a teaching tool for patients," says Gail Graham, deputy chief officer for health information management at the Veterans Health Administration's Office of Health Information. "Right now, patients can view portions of their EHRs like upcoming wellness reminders, and they can refill VA prescriptions online. Next, we are working on secure patient messaging where they can ask questions of a physician and receive answers on their personal and secure account, while keeping within the HIPAA requirements. We are trying to advance as the technology enables."

Another upcoming feature of the PHR is the ability for patients to allow others to see their records, such as a family member or other caregiver. This will be especially helpful for

accomplish their specific goals for patients. A 2006 *Los Angeles Times* article estimated that approximately 150 people can have access to an individual's records while they are hospitalized.<sup>4</sup> The intent of new privacy and security policies is to define the type and amount of information collected on a patient, limit who has access to that information and, in turn, limit the potential for misuse.

While there are many federal and state laws protecting patients' privacy, the most familiar law related to medical privacy is the Health Insurance Portability and Accessibility Act (HIPAA). This federal law allows "covered entities" to use the data for routine healthcare purposes (like treatment, payment and administrative tasks) without patients' consent. However, it does prevent the sharing of personal health information for non-routine purposes without consent.

HIPAA and other laws were created before the idea for EHRs, so although the law covers health information in electronic form, additional issues and considerations are still being worked out.<sup>5</sup> "Many of these gaps were resolved in the recent economic stimulus legislation, which made a number of improvements in the HIPAA privacy rule. Ensuring appropriate implementation of these new provisions will be key to ensuring there are sufficient privacy protections for patients whose records are stored and shared electronically," says McGraw.

Of particular importance for many chronically ill patients is access to EHRs by health insurance companies. Health insurance companies fall into the same "covered entities" category under the federal HIPAA law. They must provide patients with a privacy notice and take precautions

with information to protect patients. However, it is less of an issue that insurance companies are going to unlawfully use data, and more of an issue of *how* they are going to use the insured's information. Insurance companies do have the right to use patients' data for medical underwriting and deciding whether, for instance, a test the doctor prescribed is medically necessary. This utilization review by insurance companies is where many have concerns, because should insurance companies see something as a pre-existing condition, they can deny coverage. This is particularly true if the health plan is individually purchased. Individually purchased plans do not have the same federal protections as group (employer) plans, and that lack of protection is something that is being addressed in the healthcare reform.

Another major concern in the electronic age is security. Is the unsecured exchange of electronic information allowing patients' information to get into the wrong hands? If so, how can the government, hospitals, developers of EHR software and patients keep information secure? "Good security," says McGraw, "will keep unauthorized persons (such as hackers or hospital employees who are snooping in records of patients they are not treating) from accessing the record."

There are also concerns about whether privacy protections — the policies and standards for who can access information and for what purposes — will serve as a barrier to the ability of patients and physicians to access health information. But, that shouldn't be an issue if privacy rules are designed to allow for easy physician and patient access, while limiting or prohibiting the ability of others (such as marketers) to access the record. Today, privacy rules permit physicians to access data for treatment purposes, and patients are able to get an electronic copy of their records (if their providers keep records electronically) in a shorter period of time.

The policies and standards for internal compliance and enforcement by CCHIT were created by the American Health Information Association, the Health Information and Management Systems Society and the National Alliance for Health Information Technology, and are instrumental in the issue of security because they set standards for certification of EHR systems. Software developers are using these criteria to ensure systems can work together (interoperability) and safely. The ONC adds that "privacy and security in electronic health exchange,



the cost of this technology and how useful it will be in the day-to-day provision of care are some of the key issues that need to be addressed. We recognize the critical importance of privacy and security for electronic health information and will continue to address this issue through our policy and implementation work. The technology exists, and continues to be enhanced, to provide a secure and private environment to store and exchange health information.”

### Patients’ Role in Security and Privacy

Patients also have a responsibility to help keep their information safe as they view their records on a computer. On home computers, firewalls, virus protection and malware protection is essential. There are free and for-fee programs on the market that offer varying levels of protection, and they are updated regularly.

*The use of someone's healthcare file or medical records without their consent constitutes medical identity theft.*

Security becomes more difficult when using a shared computer, such as a library or Internet café, because it’s possible that the computer may have malicious software installed by someone looking to steal information. If a shared computer must be used to view information, first inquiring about what kinds of security scans are run on the computers is important. A location that offers more security scans and more protections will better help protect information. Also, shared computers may not have had malware installed, but someone may have inadvertently visited a website or opened an email that had malware attached. To help secure information, login IDs and passwords on a shared computer should never be saved, and at the end of each session, the browsing history and “cookies” should be deleted.

If patients feel that their personal information has been violated, they should contact the privacy officer for their health plan or provider. This is also the person to turn to if patients have trouble getting a copy of their records. When unable to resolve this issue, patients may want to

file a complaint with the Department of Health and Human Services Office of Civil Rights within 180 days of the incident. If it is determined that there is a violation, this office will impose penalties against the defendant. More information on how to file a complaint can be found at [www.healthprivacy.org](http://www.healthprivacy.org) and [www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa).<sup>6</sup>

### Medical Identity Theft — A Special Precaution

The use of someone’s personal health, insurance, social security number, healthcare file or medical records without that person’s consent constitutes medical identity theft, a serious fraud with serious financial consequences. And it also causes complications for patient care.

Government and computer security experts are working hard to provide additional safeguards in preventing medical identity theft. It is still a relatively new issue, though it is clear that the number of cases is growing exponentially. As EHRs gain ever-increasing footholds in the nation’s healthcare plan, the government is working with its own agencies, as well as private sectors, to better understand how to detect and prevent medical identity theft.

“Health information technology offers great promise to improve the health and care of every American,” according to the ONC. “Electronic health records can reduce medical errors, make care more efficient and are essential to moving our healthcare system into the 21st century.”

As 2014 nears, patients can expect to see changes in the way providers manage their care. In the meantime, many issues are being worked out, and many risks are being mitigated. ■

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# Probiotics

## for Easing Gastrointestinal Distress

Probiotics, or “friendly bacteria,” may offer promising results when it comes to soothing symptoms associated with IBS.

By Trudie Mitschang

When you think of bacteria, you probably picture disease-causing microbes lurking beneath bathroom counters or hiding in the recesses of picnic potato salad. But not all bacteria are bad — or bad for you. Probiotics — also known as beneficial or “friendly” bacteria — naturally live in the digestive tract and perform many essential functions to keep a body healthy. The term “probiotic” comes from the root words *pro* and *biota*, meaning “for life,” and is commonly used to refer to dietary supplements or foods that contain beneficial bacteria similar to those normally found in the body.

The World Health Organization (WHO) defines probiotics as “live microorganisms that, when administered in adequate amounts, confer a health benefit on the host.” Probiotics are known to restore the balance of the intestinal microflora that can become unbalanced due to illness, stress, age, traveling or the use of medication such as antibiotics. In recent years, there has been a growing public and scientific interest in probiotics and their potential

health benefits. Researchers are studying whether probiotics taken as foods or supplements can help treat or prevent certain types of illness, including irritable bowel syndrome (IBS) and various digestive problems.

While study results vary, there is encouraging evidence, especially for those with autoimmune and immune deficiency diseases, that probiotics may help treat IBS and diarrhea, especially following treatment with certain antibiotics, as well as shorten the duration of intestinal infections. In addition, research shows that probiotics may help prevent and treat vaginal yeast infections and urinary tract infections, reduce bladder cancer recurrence and prevent and treat inflammation following colon surgery (pouchitis).

Some preliminary studies also report that certain probiotics can play a role in reducing the development of allergies in children, decreasing *Helicobacter pylori* colonization of the stomach, decreasing the risk of certain cancers, decreasing dental-caries-causing microbes in the mouth, and simply keeping healthy people healthy.<sup>1</sup>

"Probiotics are controversial, but I believe that establishing a 'normal' microbial flora of the gastrointestinal tract can only be helpful," says Terry Harville, MD, PhD, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences.

### Probiotics in History

While awareness of the health benefits of probiotic-rich foods has been acknowledged for centuries (dating back to the ancient Assyrians), the actual field of probiotic study is relatively new. Russian physiologist and Nobel Prize winner Elie Metchnikoff (1845-1916) has been recognized as the first to document the link between probiotics and longevity, suggesting that consuming bacteria could have a beneficial effect on health. In 1907, he proposed that the acid-producing organisms in fermented dairy products, if consumed regularly, lead to a longer, healthier life.

Metchnikoff's theory was based on the observation that Bulgarians from the Balkan region of Eastern Europe who regularly consumed fermented dairy products such as yogurt were known for their longevity and good health. Since then, decades of microbiological and clinical research regarding probiotics and health have supported the theory that beneficial bacteria can improve key intestinal functions.

"In any condition of the GI tract where the microenvironment has been altered, inflammatory problems may arise. When a condition creates inflammation, it can further damage the microenvironment, causing cramps, diarrhea and bloating," states Harville. "The typical therapeutic approach is to use antimicrobial antibiotics to kill off the invading bacteria and fungi. Unfortunately, the antibiotics may also kill the normal-flora microorganisms. Using various lactobacilli species

such as acidophilus and bifidus at significantly high doses may counteract the bad flora and, thereby, prevent unwanted inflammation and clinical side effects."

### Probiotics and IBS

IBS is one of the most common gastrointestinal disorders. The condition, with symptoms including abdominal pain, constipation and/or diarrhea, affects up to one in five Americans and is second only to the common cold as a leading cause of workplace absenteeism in the United States.

Although IBS affects many people, it is especially prevalent among those with primary immune deficiency disease. There are many theories about what causes IBS, including an altered immune response or an imbalance of bacteria in the gut, which is why one area of growing interest in managing IBS is probiotics, beneficial bacteria that aid digestion while possibly strengthening the body's natural defenses and supporting a balance of healthy bacteria in the GI tract. While a final verdict on probiotics and their role in curbing IBS symptoms is still out, many case studies show promising results.

In a review of medical research, the American College of Gastroenterology Task Force on IBS found 11 studies in which probiotics were shown to reduce symptoms of IBS.

Researchers note that effectiveness varied depending on which probiotic was studied, with a trend toward combinations of probiotics providing the greatest improvement. This research was published in the January 2009 supplement to the *American Journal of Gastroenterology*.<sup>2</sup>

Another recent study published in the March issue of *Postgraduate Medicine* found that a strain of probiotic bacteria, *Bacillus coagulans*

*Researchers are studying whether probiotics taken as foods or supplements can help treat or prevent certain types of illness, including irritable bowel syndrome (IBS) and various digestive problems.*



## Probiotics Shopping Guide

Some of the claims made by probiotics manufacturers are hard to swallow. To help consumers sort through the hype, the International Scientific Association for Probiotics and Prebiotics (ISAPP)<sup>5</sup> has developed the following criteria to help consumers make smart choices when shopping for probiotic supplements.

**Understand strains.** A probiotic is defined by its genus (e.g., *Lactobacillus*), species (e.g., *rhamnosus*) and strain designation (often a combination of letters or numbers). The concept of a bacterial “strain” is similar to the breed of a dog — all dogs are the same genus and species, but different breeds of dogs have different attributes. Likewise, different strains of even the same probiotic species may have different attributes.

**Food or supplement** — which is better? Probiotics can be found in various foods, yogurts and supplements. Probiotic content is generally more important than the way in which they are consumed.

Any claim made on a product, no matter how general, is supposed to be truthful and substantiated — even though FDA approval is not required to make these claims.

**Do your homework.** Product claims of health benefits must be based on sound research done on the particular probiotic. The product should contain the specific strain(s) of bacteria at the same levels as used in published research. The studies should be performed in humans and published in peer-reviewed, reputable journals. Check product websites to see study results. A pharmacist or healthcare provider should be able to help consumers sort through the scientific language.

### What to look for on a label:

- Strain: What probiotic is inside?
- Expiration date.
- CFU (Colony Forming Units): How many live microorganisms are in each serving?
- Suggested serving size: How much do I take?
- Health benefits: What are the product’s main claims?
- Proper storage conditions: Does the product need refrigeration?
- Corporate information: Who makes the product, and where is more information available?

GBI-30, PTA-6086 was effective in relieving abdominal pain and bloating in subjects with IBS.<sup>3</sup> Subjects taking the *Bacillus coagulans* probiotic strain, trademarked GanedenBC30 and marketed as an over-the-counter product, experienced statistically significant reductions in abdominal pain and bloating versus baseline at each of the weekly measurements taken throughout the eight-week study. Subjects taking a placebo experienced statistically significant reductions in just two of the weekly abdominal pain measurements and saw no statistically significant effect in bloating. According to Larisa Hun, MD, author of the 44-subject study, “A combination of *Bacillus coagulans*, *Lactobacillus acidophilus* and *Streptococcus thermophilus* was previously shown in a clinical trial to significantly improve IBS symptoms, but it was not possible to determine what effect, if any, each strain had by itself.”

This study, and others like it, adds to the growing body of evidence that certain probiotics can help with IBS and may provide IBS sufferers with a non-drug treatment option.

### The Antibiotic Dilemma

Many patients with primary immune deficiency disease (PIDD) are frequent users of antibiotics. Antibiotics are powerful aids in the fight against disease, but most antibiotics not only destroy harmful bacteria that make people ill, they also wipe out the good bacteria needed to stay healthy. And it’s not just a temporary upset; the beneficial microorganisms in the digestive tract can be negatively affected for as long as six months after a typical seven-day course of standard antibiotics. Many people who are regularly prescribed antibiotics know all too well that positive effects of antibiotic treatment are often tempered by unpleasant side effects like diarrhea, which develops because the antibiotics have destroyed the friendly bacteria in the gut.

Studies have shown that if you take probiotics in food or as an oral supplement, these beneficial bacteria cultures can reverse the harmful after-effects of antibiotic treatment and prevent the growth of negative bacteria during times of stress. For PIDD patients suffering from antibiotic therapy side effects, probiotic supplementation may offer hope and relief.

However, the U.S. Food and Drug Administration does not regulate supplements, so specific claims about the effects of supplements have not been tested to ensure they are accurate. In addition, supplements should not be considered the cure-all, and spending on supplements

should be made wisely. Naturally, individuals should discuss their situation with their doctor prior to beginning any supplement regimen.

### **A Yogurt a Day Keeps the Doctor Away**

Probiotic awareness has become more prevalent in the United States in recent years; you can find probiotic supplements at most grocery, drug and vitamin stores. But in many parts of Europe and Asia, the health benefits of probiotics have long been enjoyed as part of the typical diet. This is not surprising considering that people of other nations tend to turn to foods and natural remedies to maintain their health, while Americans rely far more heavily on pills and medications. In fact, according to the International Probiotics Association,<sup>4</sup> Japanese grocery store shelves are stocked with dozens of probiotic-containing foods such as miso and tempeh, while in Europe, yogurts and fermented milks are the most widely consumed probiotic products. In the U.S., consumption of probiotic supplements far outweighs consumption of foods containing these beneficial bacteria.

Part of the reason for this is that much of the American diet is heavily pasteurized and preserved, while foods typically known to contain probiotics are either unfamiliar or unappetizing to the typical American palate. Foods like kefir (a cultured milk beverage), plain yogurt, naturally fermented sauerkraut and kimchi (a Korean pickled vegetable dish) are unlikely to replace mainstream American meals and snacks, regardless of their health benefits.

Thankfully, many American food manufacturers are catching on, and more and more familiar foods are now being packaged with "live active cultures," which could make it easier for people to get their daily dose of good bacteria. Foods to try include select cheeses such as Kraft's LiveActive natural cheese snacks (which contain the probiotic *Bifidobacterium lactis*) and Lavarone Bros. Specially Selected Amish Yogurt Cheese (prepared with the probiotic live cultures *Lactobacillus acidophilus* and *bifid bacterium*). Other good sources of probiotics include blue cheese and other aged

cheeses. Probiotic-rich cheeses often feature words such as "live culture," "active culture" or "probiotics" on the packaging. Other products to try include Dannon Activa Yogurt, DanActive Dairy Drink, Sunny Crunch Probiotic Chewy Cereal Bars and Kashi Vive Probiotic Digestive Wellness Cereal.

It should be noted that there have been problems in the U.S. with unpasteurized products causing severe, and sometimes deadly, *E. coli* infections. These issues are particularly problematic in patients with a chronic disease, so caution should be taken when consuming such products.

### **Probiotics: Do They Spell Relief?**

Individuals who suffer from IBS or other chronic digestive disorders have undoubtedly tried multiple courses of treatment, from medications to dietary restrictions, with varying degrees of success. If considering probiotic supplementation, the topic should be discussed with the patient's doctor. Studies on the effects of probiotics on patients with IBS are

ongoing, and while some have shown that probiotics are helpful to IBS sufferers, not all patients experience positive results. Still, clinical trials have shown no harmful side effects. Of course, a doctor should always be consulted before starting any treatment or regimen. A specialist can help to find an effective IBS treatment to suit unique needs, and can monitor progress toward healing. For more information about probiotics and probiotic supplements, visit [www.usprobiotics.org](http://www.usprobiotics.org). ■

*For PIDD patients suffering from antibiotic therapy side effects, probiotic supplementation may offer hope and relief.*

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**TRUDIE MITSCHANG** is a staff writer for IG Living magazine.

# Is Your Infusion Nurse Qualified?



To ensure quality care, patients should look into whether their nurse has the proper training.

By Ronale Tucker Rhodes, MS

Infusions are hardly joyful, but the experience can be made worse if a nurse provides substandard care. Performing infusions and being prepared for possible side effects and complications takes skill that is learned only through experience and advanced training. And, while it may be assumed that the nursing professional performing the infusion would have the proper training, that is not always the case. Patients, then, would be wise to understand the responsibilities of an infusion nurse and take an active role in ensuring that their nurse is qualified to provide the proper care.

## The Role of an Infusion Nurse

Infusion nurses are responsible for providing the safest possible care to patients who undergo intravenous (IV) infusions. Because no two patients are alike, nurses must take special precautions to understand each patient's medical condition and treatment needs. In addition, they must recognize that tolerances to immune globulin (IG) infusions vary among patients, as do reactions both during and after treatment.

Aside from a knowledge of nursing practices in general, which includes anatomy and physiology, infusion nurses must

understand the vascular system and its relationship with other body systems and infusion treatment modalities.<sup>1</sup> In addition, they must participate in the patient's ongoing healthcare plan, be skilled in infusion therapies, have knowledge of state-of-the-art technologies associated with infusion therapies, understand the psychosocial aspects of care, and interact and collaborate with the patient's healthcare team.

Specifically, infusion nurses must be trained in the clinical uses for and be familiar with the diseases that are treated with IG replacement therapy.<sup>2</sup> Understanding that no two IG products are the same, they should familiarize themselves with product preparations, stabilizers and IgA levels in the different products. Prior to infusing, they should be familiar with the key assessments, including the brand, product integrity and patient's status (premedication, breathing, hydration, weight, etc.). With each infusion, nurses should log the blood product, lot number(s), expiration dates and dosage in the patient's record and a central database. And, they should be aware of what types of adverse reactions can occur and how to manage them with specific interventions.

## Training: What Is Required

All of this required specialty knowledge necessitates that the infusion nurse be a “specialist,” rather than a “generalist.” This means they have acquired the necessary specialty practice knowledge. “A specialist is a generalist, but a generalist has not acquired the knowledge and skill in a defined area to be designated a specialist,” according to the Infusion Nurses Society of America. “The foundation of specialty practice is based on the knowledge gained from general nursing education and a concentrated study in a selected clinical area of nursing.”<sup>1</sup>

According to Nancy Creadon, RN, vice president of VaxAmerica, a subsidiary of NuFACTOR, the specialty pharmacy of FFF Enterprises Inc., “All nurses are trained in starting IVs and what the basic infusions are. As nursing students, we study IV fluid chemical makeup and effects on the human body. [But], most infusion nurses have to further their education in an effort to be proficient and up to date on infusion therapies.” Infusion nurses are concerned about not only the drug added to the IV solution, but they must also monitor the “base solution” and the secondary effects it has on the body, such as potential fluid shifts and overhydration.

Most nurses who perform infusions gain experience by working in hospitals in critical care areas, says Creadon. However, there is a certification available, known as the Certified Registered Nurse, Infusion (CRNI), that will provide nurses with the knowledge needed as a specialized infusion nurse. Few nurses, however, actually seek this certification. A CRNI must pass an exam that covers various levels of IV care, including starting IVs of various sizes and managing infusion calculations and rates. “For example, some infusions are tapered up and down, some are based on a patient’s weight, while others are based on a person’s renal function,” explains Creadon. The exam also covers different types of IV therapy, including antibiotics, nutritional therapies and IG therapies. A CRNI is the only certification for infusion nurses and is offered by the Infusion Nurses Society of America. Once obtained, the certification is good for three years. After that, nurses

must complete an additional 40 educational units to maintain CRNI status.

This is not to say that infusion nurses who do not acquire a CRNI aren’t qualified. Many are, but they may have some limitations. “While I do believe many nurses can acquire and maintain the same skill level as a CRNI with years of infusion therapy practice,” says Creadon, “they may still lack knowledge and new information and techniques, as they are not required to participate in target CE [continuing education] programs to maintain the certification on a yearly basis.”

Having a CRNI would be preferable, but if patients have a nurse who works well with their doctor, who understands their disease and who is willing and open to learning more, there is no need to change nurses because they lack the certification. “The key is open communication and not to be afraid of asking questions,” explains Kris McFalls, *IG Living’s* patient advocate. “Ask them if they have infused IG and, if

so, how many patients they have infused. Also ask the nurse how often they start infusions. A good infusion nurse will start infusions on a regular basis.” But, adds McFalls, if the answers patients receive are not satisfactory, they shouldn’t be afraid to ask for another nurse.

## Infusions and Peace of Mind

All patients want the peace of mind of knowing that their infusion nurse will provide them with the safest possible care during IG therapy. And, while there can be

a significant difference in the care a patient receives from a certified infusion nurse, says Creadon, many nurses without certification have the experience necessary to provide excellent quality care. Ultimately, it will be up to patients to assess their own situations, ask questions and determine whether their infusion nurse is the right one for them. ■

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1. Infusion Nurses Society of America. Scope of Practice. Accessed at <http://www.ins1.org/i4a/pages/index.cfm?pageid=3349>.
2. Immune Deficiency Foundation. *IDF Guide for Nurses*. IDF, 40 W. Chesapeake Ave., Suite 308, Towson, MD 21204, 800 296-4433, [www.primaryimmune.org](http://www.primaryimmune.org).

**RONALE TUCKER RHODES, MS**, is the editor of *IG Living* magazine.

*A CRNI is the only certification for infusion nurses and is offered by the Infusion Nurses Society of America.*

# Let's Talk!

By Shirley German Vulpe, EdD

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](mailto:editor@IGLiving.com).

*Donna is 61 years old and has myasthenia gravis (MG), a chronic disorder characterized by weakness and rapid fatigue of voluntary muscles of the face, eyes, eyelids, mouth, throat, arms, legs and lungs. Weakness is caused by damaged and/or destroyed chemical receptors of muscle nerves, which affects a person's ability to chew, swallow, talk, breathe and move their arms and legs. Donna also has type 2 diabetes, which is a possible side effect of prednisone, an artificial steroid used to treat MG. In addition, she has Hashimoto's thyroiditis, an autoimmune disease resulting in insufficient thyroid hormone. Symptoms of Hashimoto's include fatigue, weight gain, forgetfulness, muscle weakness and cramps, puffy face, constipation and dry skin and hair.*

**Shirley I** When were you diagnosed, and what happened during the diagnostic process?

**Donna I** I was diagnosed when I was 56. I was feeling run-down and just not feeling well, and my doctor did my blood work, but everything looked good. So I decided to exercise in the gym and went hiking as usual, but that just made things worse. Finally, I sent an email to my sister

who works as a clinical research coordinator at Columbia Medical Center in New York. I explained my symptoms to her, and the neurologist she works with said it sounded like MG. It took four months to get an appointment to see a neurologist and five minutes for him to diagnose MG. I started to cry because "it"

even pronounce the disease. So educating myself on what this was about was number one. It helped me to have some control, and I realized I had to work with my MG and not against it. I researched everything on the Internet, including support groups and available treatments.

***“Educating myself ... helped me to have some control, and I realized I had to work with my MG and not against it.”***

finally had a name. He told me that many of the symptoms could be managed by medications and treatments, but that the disease has no cure. He prescribed Mestinon, and within one week, I was in a major crisis and had to be admitted to the hospital and put on a ventilator.

**Shirley I** Were there any red flags, tests, etc., that stand out now?

**Donna I** Yes. I didn't realize how important I was to the process. When this all started, I couldn't

**Shirley I** If you knew then what they know now, what things would you have done differently?

**Donna I** I probably would not have tried to be so in control. In the hospital, my doctor had a psychiatrist come to talk with me and he explained that I was suffering from post-traumatic stress disorder from everything that was happening. That helped me to be kinder to myself. It was going to be a process that would take time. My life would never be what it was, and I needed

to trust that what was happening was going to be for my better good.

**Shirley I** How do you receive IG?

**Donna I** I used to have IVIG as a hospital outpatient, but venous access was getting more difficult, and I did not want a port. Then I found out about subcutaneous immune globulin (SCIG). I emailed Kris McFalls, *IG Living's* patient advocate, who called me that very day and I explained my situation. She referred me to NuFACTOR (a specialty pharmacy) for many of my questions. My doctor had never heard of SCIG for MG, but he said that if I brought him literature he would look at it. With NuFACTOR's help, as well as the name and phone number of Dr. Melvin Berger, a leading authority on SCIG, I had the information I needed. My doctor telephoned Dr. Berger and discussed the pros and cons. I started SCIG last July and it worked well for a while, but recently, I had a crisis caused primarily because my prednisone was lowered. I was admitted to the hospital for plasmapheresis (a treatment in which the antibodies in the plasma of the blood are removed), and the doctor increased the prednisone levels as well. After being discharged, I had IVIG two times before resuming my regular SCIG treatments of two times a week.

**Shirley I** Have you had any problems receiving or paying for IG?

**Donna I** I have been fortunate. I was on COBRA, and when it ran out, I tried to extend it, but I was refused because I have MG. Luckily, New Mexico has an insurance pool for

## Resources

1. Myasthenia Gravis: [www.mayoclinic.org/myasthenia-gravis](http://www.mayoclinic.org/myasthenia-gravis)
2. Hashimoto's Thyroiditis: [www.womenshealth.gov/FAQ/hashimoto-thyroiditis](http://www.womenshealth.gov/FAQ/hashimoto-thyroiditis)
3. Myasthenia Gravis Foundation of America: [www.myasthenia.org](http://www.myasthenia.org)

people with catastrophic illnesses, which has a \$500 deductible and \$2,500 maximum out of pocket per year, and then 100 percent coverage after that.

**Shirley I** Has SCIG helped?

**Donna I** It has helped me to have more control over my treatments. I can do them in the privacy of my home on my own time instead of going to the hospital.

**Shirley I** Have you received any support?

**Donna I** My family, especially my sister, help me maintain perspective. My friends, who have always listened, help me to carry on and give me tough love when needed. *IG Living* magazine and Kris McFalls have helped me immensely; the articles help me to understand what other patients are experiencing.

**Shirley I** What is the best advice you have received?

**Donna I** Occasionally someone says or does something to help you get to the next level of understanding or to pull you out of your pity party. At first, their words don't strike you as good advice, but on reflection, they are. An acupuncturist I was complaining to told me that my illness was my new identity. She said I was acting like the disease was me, and I needed

to step away and not make it who I am. I was angry and offended, but then I realized I did not want that!

**Shirley I** Do you have any final words for those who read this column?

**Donna I** Don't give up. Don't take sentences handed to you. Be one of your own doctors; bring your own experiences to discussions and keep asking questions. Listen to your body. I should have been listening better before this recent crisis because the symptoms were there. But I wanted to be off of prednisone, and I was not paying attention. Embrace the challenge, face your fears and try to keep your ego out of the way. 🍀



**SHIRLEY VULPE, EdD,** has a doctorate degree in educational administration, a master's in early childhood special education, a BSc in occupational therapy and a diploma in physical and occupational therapy. She worked for 38 years specializing in setting up rehabilitation and early childhood special education programs. Shirley is now retired due to two autoimmune diseases: common variable immune deficiency and chronic inflammatory demyelinating polyneuropathy. She has been married for 45 years to a physician, is the mother of two children and the stepmother of five.

# Ask Kris

By Kris McFalls

Have a question? Kris McFalls, *IG Living's* patient advocate, is eager to find answers. Email them to [editor@IGLiving.com](mailto:editor@IGLiving.com). Your confidential information will not be used for any purpose but to communicate with you about your questions.

**Loyda:** I get infusions of Gamunex. The nurse at the hospital flushes my line with saline before and after the Gamunex. Is this OK?

**Kris:** Normal intravenous (IV) tubing may contain more than a gram of immune globulin (IG) once an infusion bag is empty. To keep from losing this last amount, many physicians and patients insist that the line be flushed. But care must be taken to use the correct product for the task. The Gamunex insert clearly states that the product is not compatible with saline. I asked NuFACTOR pharmacist Amy Ehlers to comment further.

**Amy:** It's true, Gamunex is not compatible with normal saline (NS). When mixed with NS, it forms a precipitate (turns cloudy and/or chunky). Gamunex has to be first flushed with 5% dextrose in water (D5/W). There is no reason to flush with NS if flushed with D5/W. It's also acceptable to flush with D5/W and then flush with heparin, or flush with D5/W and then pull the peripheral site.

Flushing with NS is not as much of an issue with a peripheral IV because the line is discontinued at the end of treatment. But with a port or PICC (peripherally inserted central catheter) line, it can cause more of a problem. Oftentimes, knowledge of how products interact is key to a successful outcome.

**Patient update:** Loyda's question was part of her search for causes of the unusual reactions she experienced after

her infusions. When she discussed her concerns with her doctor, as well as the instructions in the Gamunex insert, her doctor wrote an order to flush only with D5/W. Happily, Loyda no longer has those particular reactions.

**Duane:** My insurance company recently told me I had to change specialty pharmacies. My current provider gives me a waiver for my co-pays and provides me with a nurse in the evenings and on the weekends. I drive a truck for a living and cannot be home during the day. Do I have any choice in the matter?

**Kris:** It is quite common for insurance companies to either acquire their own specialty pharmacy or contract with one source for specialty drugs. This is usually done to keep costs down. Most of the time, you have no choice but to switch. The best thing you can do is to make a good faith effort to make the new system work for you. If after making a good faith effort, the new system does not work, your insurance company may be more willing to make an exception in your case. The best way to start is to call the insurance company and ask for a case manager. Explain your situation, and ask for help.

Most IG providers have some form of financial aid, but you will have to ask for it, and the guidelines for receiving help differ among companies. When you call the new specialty pharmacy, ask to speak with someone in reimbursement. From there, ask if they

have a financial aid or compassionate care program. Request an application and fill it out. Keep in mind that guidelines often change year to year, and you may be asked to fill out a new form every year. With reimbursement margins getting smaller and smaller, hospitals and specialty pharmacies alike are experiencing the need to cut back. Therefore, you may qualify for help one year but not the next.

**Patient update:** While working with Duane, I discovered that his new specialty pharmacy provided only the medication. His supplies were sub-contracted out to a second provider and the nursing to a third provider. Communicating with all three providers proved to be a daunting task. Fortunately, Duane was able to get a caseworker at his insurance company to help with the process. Duane and I spoke together on the phone with his new specialty pharmacy and successfully got all parties coordinated in time for Duane's infusion. Once Duane was connected with one person at the specialty pharmacy who took charge of the case, his needs were met. ■

*Amy Ehlers is the director of pharmacy at NuFACTOR Specialty Pharmacy.*



**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.

# Loving Life

By Ever Feckske



**ARE THERE MORNINGS** when you open your eyes and all you want to do is close them again? Are there days when you become so frustrated with life that you just want to lock yourself in a room with a pint of ice cream and watch Oprah? How about those days when nothing goes as planned, when you don't get what you want or when your problems keep multiplying? We all experience those days, and if we allow it, they cause us to think negatively. It's easy to think of ourselves as victims. But, what if we could turn these negative thoughts into positive thoughts? Would you? I know I would.

I have been trying to make changes in my life to avoid thinking of myself as a victim. Foremost, I am trying to think more as I did as a child. As children, we were happy and content with being ourselves, and we

sincerely believed that we were worthy of the attention and the love that we were given. But as adults, that often changes and insecurity takes the place of contentedness.

So, I'm trying to ensure that my thoughts come from a place of love. It is possible that, as adults, we can change our thinking to be more positive. Instead of saying, "I really don't

want to spend half of my day infusing," try saying, "I am going to my infusion today because it helps me heal, and I want to be healthy." Or, when frustrated with your doctor, instead of thinking, "What an idiot! What is wrong with him? What do I have to do to get things done?" try to think constructively and say, "I know you are doing the best you can, but don't you think there is something more we can do?"

Most importantly, I am trying to make the thoughts about myself come from the love I have for myself. Go ahead: Talk yourself up! You deserve it. Say things like, "I am a strong person." "I am a good person." "I am worthy of good things." We need to imagine what we really want in life and embrace it. Life is about growing into who we want and mean to be. So, try to think of your "problems" as "projects" that,

if addressed positively, will help you to grow and become better.

Over time, I have learned to embrace my illnesses. All of my ailments are not who I am, but they absolutely are a part of me. I am proud to say that I have common variable immune deficiency and interstitial lung disease. And guess what? I am a happy person!

The truth is: We become the emotions that we allow to dominate. If we are sad, angry and negative, well then, we will become sad, angry, negative people. But if we are grateful, happy and positive, we will be grateful, happy, positive and abundant people. And we all deserve that!

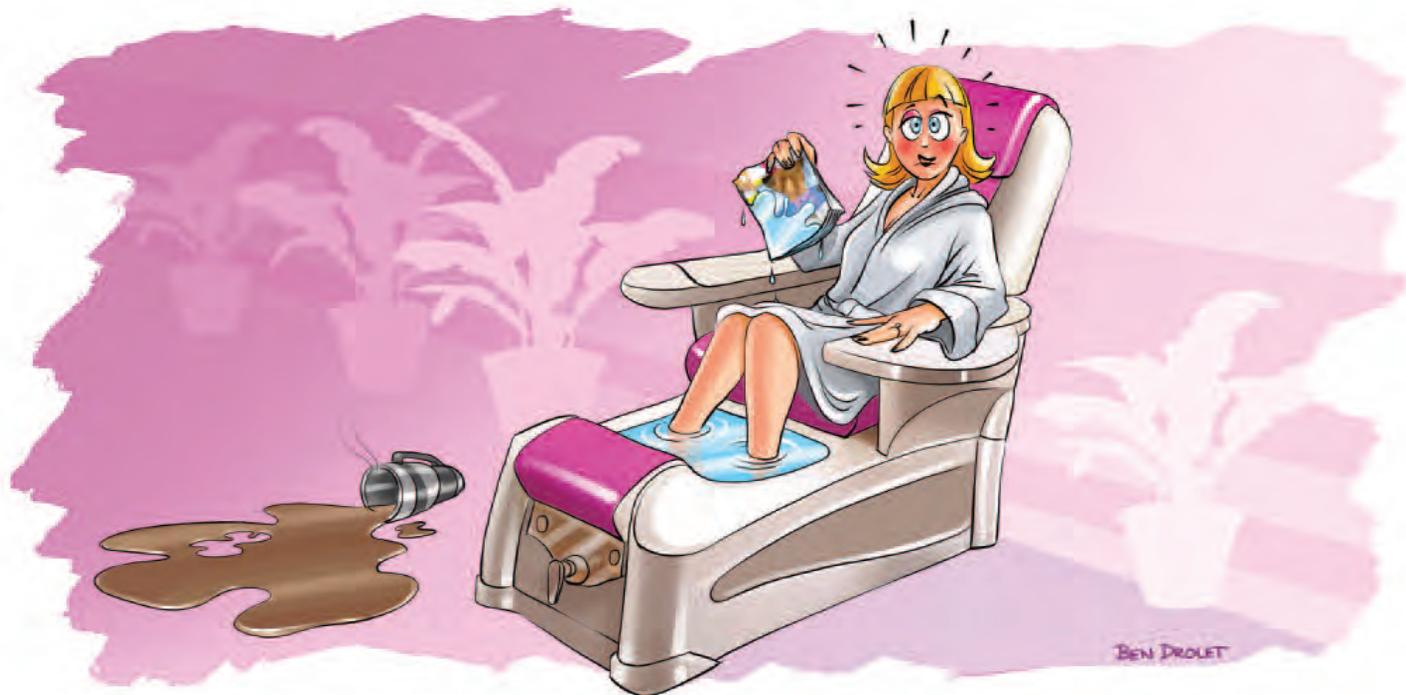
We are not victims. We don't want pity because our bodies may not work perfectly. More importantly: We must not pity ourselves. The best and greatest gift of healing that we can give ourselves is unconditional love and acceptance. So heal yourself the best you can by loving who you are. Love your life, and life will love you back. ■



**EVER FECKSKE** was diagnosed with CVID and interstitial lung disease in 2004.

She is a fashion design student, loves spending time with her boyfriend, family and bulldog, Dunkin, and can't get enough of writing, cake decorating and anything that sparkles!

# Caught Ya!



By Cheryl L. Haggard

**IS DISCIPLINING YOUR** PIDD kid as hard as it is for you as it is for me? Don't get me wrong. When Calvin was chasing the neighbor's cat with a nail-infested two-by-four, he received some "wisdom where the sun don't shine," if you know what I mean! My point is: It's hard to be the disciplinarian of a child whose shadow is marred by an IV pole.

To ease my parenting guilt (which lies heavy on me like hot fudge on a sundae), I momentarily pulled myself out of teaching retirement in hopes I could "catch the kids doing something good," and reward them in some small, but meaningful way. The Great Haggard Behavior Modification Experiment was working until I brought my own personal hygiene

habits to dinner.

Half confident and half hiding under the table, I asked my husband, "Mark, do you think I could swing a pedicure sometime this weekend?"

"Have I caught you being good?" Mark snickered.

"What's a pedicure?" our 7-year-old daughter, Molly, interrupted with a mashed potato and gravy accent.

I was going to ignore my precious daughter's inquiry. My occasional pedicures keep me from going street rat crazy from the raising of three chronically ill children and my recent diagnosis of a painful autoimmune disease. If Molly finds out what a pedicure entails, including getting my toenails painted, I'll never go solo again, I thought!

"I wanna go," Molly begged in delight.

Then I thought, with selfish desperation, she'll never go after I explain pedicures include cutting away of your cuticles, grating the skin off your heels, screaming hot water and a terrorizing massage chair that jiggles your belly fat!

"Mom, please?" Molly pleaded. "I know!" Molly grinned as a light bulb "binged!" over her strawberry blond head. "Haven't I been a really good sub-Q patient?"

And there it was. She had been amazing switching from IVIG to SCIG. Molly quickly embraced the frequent infusions and the tiny sub-Q needles — all without a peep or our beloved Nurse Nancy.

"I guess I have 'caught you being good!'" I conceded with enthusiasm.

So over the weekend's "boy's only" camping trip, Molly and I found ourselves heading to the salon (after I took out a personal loan from the bank to pay for our planned pedicures).

"OK, sis, I know you're excited," I said gently. Molly was so charged up about our girly outing, she hardly slept the night before. And because she was bouncing around like a monkey high on a triple shot of espresso, we needed a lesson in pedicure etiquette.

"Molly, pedicures are a relaxing retreat; some girls might even fall asleep, exhausted from raising their kids!" I explained.

"Oh, so you want me to be really quiet and sit still, is that right? I mean, do I need to keep my lip zipped and crisscross applesauce just like this, Mom? Mom, see? Look at me! AHHHHUUUUUUUMMMMM." Molly peppered me with questions. I glanced at her while squeezing the steering wheel, gritting my teeth. Molly's eyes were closed, hands appropriately locked in meditation mode as her body resembled a stressed-out Tibetan monk, looking anything but peaceful. Her rapid-fire questions vexed me to the core and I concluded: She's gonna blow!

The familiar hot water and gentle greeting from my nail technician, Gina, began to soothe my tension as my princess settled in next to me. Molly giggled as bubbles from the soaking tub tickled her toes. "Thanks, Mom," she said as her sea-green eyes grew heavy. "This is gonna be great!"

The string of events that follow must have been a freak of nature, or qualifies as unexpected acts of God not covered

in insurance policies. Reaching for my untouched travel mug of steaming joe, I proceeded to knock its precious contents onto the tile floor. Horrified, I slid out of the chair to help clean up the mess.

"Don't worry about it, Cheryl. It happens all the time!" Gina cooed.

It may happen all the time to you, but not to me, I groaned to myself.

I checked on Molly; she was sitting comfortably, playing with the adjustments of the massage chair.

Confident Molly just might avoid disaster, I situated myself back in my chair ready to relax and catch up on weekly gossip in a smut magazine. My eyes began to focus in and out as I felt myself drifting to sleep. I was suddenly awakened by the unfamiliar feeling of wet paper at my feet.

"Oh my gosh, I am so sorry! I must have started to fall asleep!"

Gina started to laugh as Tom Cruise bobbed up and down on my big toe. Molly, Gina and a few other salon-ees really cracked up watching me "wring-out" The Housewives of New Jersey, Brangelina and Kate Gosselin.

Finally, Molly and I made it to the nail-drying station. Five more minutes and you're outta here, I comforted myself.

"Now, don't touch anything, Molly."

"Mom, what are the light bulbs for?" she asked.

"Don't touch them!" I shot back. "Don't let your toes hit them. They are drying your toes."

It's as if I had orchestrated it, or someone who had it out for me ordained it, but as I was reaching for my wallet, there was a tinkly crash and shards of glass splattered in every direction. Razor-sharp pieces of a drying light bulb lay helter-skelter on

the slick tile floor and the marble drying station. Gina rushed over to make sure Molly and I weren't cut.

"I didn't touch it!" Molly insisted. "I didn't touch it! Mom told me not to touch it and I didn't!" I looked up as if in slow motion. As I peered around the room, instead of shock, I saw smiles and heard laughter. Knowing it was my fault (I felt my elbow catch the bulb as I grabbed for my purse), I apologized to Gina and put a little extra in for tip, bulb and smut.

Driving home, I felt humiliated leaving Molly confused, or so I thought.

"Mom, that was wonderful!" exclaimed Molly.

Wonderful for you, I thought. "You didn't spill coffee, drown Tom Cruise and create a hazardous work environment all in one day."

"But I caught ya being good," Molly announced innocently.

"What do you mean, Molly?"

"You made a room full of people laugh!" she giggled.

"I guess I was good, huh?"

Molly nodded in my direction and looked out the passenger window, her tiny toes pretty in pink. In all the frustration of parenting sick kids, I realize when I am crying over spilt milk (or coffee), the tears I shed blur my vision. And when you can't see, it makes it hard to "catch ya" being good. ■



**CHERYL HAGGARD** is a stay-at-home mom and has three children, two of whom have combined variable immune disease. She and her husband, Mark, also operate Under the Hood Ministries at [www.underthehoodministries.org](http://www.underthehoodministries.org).

# End Zone Celebrations

By Mark T. Haggard



**AH, FOOTBALL SEASON.** It's the most wonderful time of the year, when plants start dying and pigskins start flying — and players celebrate in the end zone.

As a football coach, I have some strong opinions about how players should conduct themselves on the field — especially in the end zone. I don't particularly like it when a player draws attention to himself and away from his teammates. Consider the wide receiver who catches a pass and reaches paydirt. When he spikes the ball or does a dance or pulls a Sharpie out of his sock to draw attention to himself, it's as if to say, "Look what I did!" while 10 other guys stood by and watched.

Is this team play? Let's look at what the 10 other guys did during the play, shall we?

The quarterback spent numerous

hours watching film before the game so that he would know what each defender was going to do on each snap of the ball. He stood back in the face of a rush, potentially a blitz, and delivered a strike to the receiver.

The other receivers on the team had to run just as far and just as hard as the receiver who scored the touchdown; if they hadn't, the defense would have moved toward the receiver who scored and covered him even tighter. In other words, the other receivers' actions were just as important as those of the guy who scored.

The "Big Uglies" on the offensive line have the toughest job of all, and I'm partial to them — and not because they're big and ugly or because I am big and ugly. These are the guys with whom I have spent most of my coaching life. I have simply asked them, every play, to put their face in some

300-pound guy's sweaty chest and drive their feet — all of this while the guy on the other side is doing the same to them. It's just not natural; it's just not right.

So, why should one guy get all of the credit? No way! I tell my players: "Act like you've been there before. Turn around, hand the official the ball and prepare for the next play." Or, "Celebrate with your entire team!"

I recall watching the Washington Redskins in the 1980s when their receivers were known as the "Fun Bunch." When one guy scored a touchdown, the rest would gather around him in the end zone and they would jump together and do a collective high five.

I remember seeing the University of Georgia play the University of Florida a few years ago — a long-standing rivalry game known as "The World's Largest Outdoor Cocktail Party." Georgia scored first, and the entire team ran onto the field to celebrate the score. Georgia was flagged 15 yards for excessive celebration, but the Bulldogs still beat the Gators. That's how players should celebrate; they should get excited!

I coach the defense at the high school where I work. In practice, every time my guys get a turnover and score against the offense, I want them to celebrate. "It's football," I tell them, "so get excited!"

They've become quite creative in the way they celebrate: After one score, my team gathered around and

one player threw the ball in the air... When it hit the ground, they yelled, "Boom!" jumped back and fell down like it was a hand grenade. After another score, 10 players lined up in a triangle; the guy who scored the touchdown rolled the ball at them, and they fell over like bowling pins. All I could do was laugh with joy at their antics.

My son has gotten into the act since visiting practice. After an IVIG treatment a couple of months ago, he finished getting deaccessed, jumped from the couch and did something that was an awkward combination of the "Cabbage Patch," the "Running Man" and the "Sprinkler."

"Son, what are you doing?" I asked.

"Dad," he answered, "you always want your guys to celebrate on the field. I'm celebrating!"

Caleb's excitement started rubbing off on me. I considered the whole "team" issue: Play together, work together and celebrate together. Then I wondered, "What about Caleb's team that puts his life-giving treatment into place?" My thoughts turned toward the volunteers who give up their time, take a needle in their arms and donate their life-giving blood. I envisioned the researchers at the pharmaceutical companies who take the blood, spin it in a centrifuge, draw out the immune properties, and produce a safe, infusable form of IG. I thought about the nurses who oversee the infusions,

and the doctors who research the disease and establish regimens to bring us the best health possible.

We need to all get together someday and do some kind of celebration — be it a huge collective high five, bowling pins or some awkward version of the "Running-Cabbage-Sprinkler."

It's our life! It's our health! Get excited! 🍀



**MARK 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](http://www.underthehoodministries.org).

# Extraordinary Measures for an Ordinary Life



Lilly Grossman has mitochondrial disease, and for her and her parents, life is challenging, yet happy. This is their story.

By Rachel Morton

Lilly Grossman, daughter of Gay Johnson Grossman and her husband, Steve, is in many ways a typical 12-year-old girl. She likes baby dolls and ballet. She is passionate about pink. She adores Hannah Montana and Abercrombie and is beginning to find boys interesting. She sometimes thinks her parents are clueless, and she likes to

tease her dad. With her long, wavy blond hair, big smile and a twinkle in her eye, Lilly is her parents' pride and joy. Last year, she was in Honors Choir, and when the choir trooped over to a television studio to film its holiday concert, Lilly was part of the action. This was an exciting afternoon for most of the kids, but for Lilly, the drama

extended beyond the musical score and the thrill of being on television.

## Living with Mitochondrial Disease

Lilly has mitochondrial disease, a rare and often disabling illness that can make summoning the energy to do something like stand and sing nearly impossible. That day her mother watched in dread as the hot television lights blared down on the children. Heat affects Lilly immediately and drastically, sapping her strength and muscular control. As Gay feared, Lilly keeled over sideways into a bank of poinsettias. Gay rushed up to lift her daughter offstage and cool her down, glad that Lilly had seized her chance in the limelight even if it didn't start well.

Being an advocate for Lilly is now Gay's primary job. Every day, all day and sometimes long into the night, she takes extraordinary measures so her daughter can have an ordinary life. A child with a chronic debilitating illness would be a huge challenge to any parent, but Gay and Steve have met this challenge with determination and grace. Gay herself is surprised at how her priorities changed when the extent of Lilly's needs became evident. But rather than plunge into a depression or become paralyzed with the weight of her responsibilities, Gay found that caring for Lilly has given her life purpose and meaning and strengthened the bonds in her marriage.

This is a busy family. In addition to supporting Lilly's participation in school and extracurricular activities,



Gay works full time designing high-end writing paper for her company, Letters From Lilly, Ltd. Steve sells document-management software for the pharmacy industry. And they are both active in school and community and very involved with the United Mitochondrial Disease Foundation, giving support and advice to parents of children who have been diagnosed with this immunological disease that can severely affect a child's body and mind. Some kids can't walk or talk. Some need to use feeding tubes or oxygen. Some, Gay says grimly, "are severely compromised in all their critical body systems. We're lucky. Lilly's bright, she's funny. She can tell me she loves me."

Gay and Steve are now veterans, having been inexperienced parents themselves 12 years ago, when they first noticed that Lilly was not progressing in the same way other children her age were. They began taking her to doctors and hospitals in what seemed like a never-ending process of trying to find out what was wrong. One day, Gay's best friend arrived at the hospital to keep her company. "It is so heart-breaking," this friend told Gay, "to

walk through these hallways and see these parents and the sick children." Then, she looked at Gay and said, "Oh my god, you're one of them."

"It's a new club," says Gay. "The club of parents with sick children. Sometimes you're in clubs you don't want to be in."

### Changed Lives

Membership in this club has changed their lives totally. Gay and Steve moved from Cleveland to San Diego, away from all their family and friends, to be in a place that is better for Lilly. Cleveland's temperatures were too extreme, the icy sidewalks unnavigable for a little girl with a walker. And the hospital at UCSD in San Diego is one of the world centers for mitochondrial disease research. They have changed jobs — both Gay and Steve developed home-based businesses. And they've both turned their acute intellects toward understanding this rare disease and learning how they can best help their

little girl participate in life to the fullest.

This has involved a fair amount of advocacy, educating themselves and others, and a stubborn insistence that opportunity not be denied Lilly because of her disability. Gay developed this determination during the years it took her to get a diagnosis for Lilly, years when no one in the medical establishment could find anything wrong with her daughter.

The disease began slowly for Lilly. Gay did not begin to get concerned about her daughter's progress until she was 9 months old. Doctors thought she was just slow at reaching those physical milestones — pulling herself up, sitting, walking. But a mother knows, and as the months wore on, Gay became more and more convinced that Lilly had a serious health problem.

But although she might have been developing slowly, Lilly was a pretty little girl with cognitive acuity and no obvious illness, so doctor after doctor told Gay there was nothing wrong.



One doctor suggested that perhaps the problem was Gay's, and he requested that the next time she came to see him, she should bring her husband. When Lilly was 3 years old, Gay and Steve got a diagnosis at the internationally renowned Cleveland Clinic. Though Gay still harbors bitterness toward some of the doctors and hospitals she took Lilly to before the Cleveland Clinic, she has moved on. She has more important things to do. If there's one thing she's learned, it's that in her life,

ness that people have shown her and Lilly. Just when she thinks she is going to have to "strangle someone" who might be about to prevent Lilly from participating in some activity, that person shows an open heart and includes Lilly with warmth and love. That afternoon when the choir was being filmed, Gay assumed that Lilly's performance was over, but the music director surprised Gay by declaring that until Lilly recovered and returned, the show would not go on.

ease, and there is no cure, although for some people treatments can be helpful. Most children seriously affected by the disease won't live beyond adolescence.

In Lilly's case, she tires easily and has little muscle strength or stamina. Walking, talking, eating, even breathing and sitting take a lot out of her. She has tremors at night that leave her screaming with pain from muscle cramps. She can't hold a pencil, so she uses a computer to do her schoolwork. She uses a walker to get around and increasingly needs a wheelchair. Temperature affects her drastically. She overheats easily and her body just "wilts," like a flower out of water. When Lilly is depleted, she can't hold her head up, and she can't speak without superhuman effort. She needs immediate attention to replenish her energy and restore her equilibrium.

What she eats has a huge effect on Lilly's condition. Over years of trial and error, Gay and Steve have found foods that Lilly can tolerate. They include organic fruits and vegetables, bison meat, goat milk, oat flour and organic honey. Minor variations from these specific foods can cause a severe reaction. Even changing the brand of a specific product can affect Lilly for hours or even days. And she has to eat an enormous amount of food just to have enough energy for daily living.

Yet, in most ways she is a normal pre-adolescent girl. She has a cell phone and texts her friends. She likes to go to the beach, where her dad helps her ride the waves on a boogie board with him. Lilly is smart and does well in the public school, where she is in a regular classroom, though Gay says, "the adjustments we make to make that happen are huge."

Because she can't use a pencil or pen, Lilly uses a computer with special



there is no time for complaining.

She has a role model here. It's her delightful, funny, intelligent daughter, Lilly. If Lilly isn't complaining — stuck in a wheelchair, unable to join her friends in the simplest physical activities — then Gay feels she certainly has nothing to complain about.

Gay has also been surprised and grateful at the generosity and good-

### **About Mitochondrial Disease**

Mitochondrial disease is a genetically transmitted illness that can have a wide variety of symptoms. It affects the mitochondria, which function in every cell in our body and affect how energy is created and used. It can manifest itself in numerous ways — it can be mild and treatable, or cause serious physical and mental disabilities. It is a progressive dis-



software. An aide meets her at the curb every day and helps her set up her computer and papers at her desk, then steps to the side of the room, ready if Lilly needs her again. The aide scans in her homework so Lilly can keep up with the class, doing exactly what they are doing, but in a different medium.

Once a month, her life comes to a screeching halt, when Lilly has to go to the hospital for a two-day IVIG infusion, which helps her marshal enough energy to keep living that ordinary life. Lilly hates these infusions. What 12-year-old could bear sitting in a hospital for two days being hooked to a machine?

"These are not happy days," Gay says simply. "She cries, she's a puddle. But if she doesn't have the infusion, I am carrying her everywhere. I have to feed her and bathe her. She gets very stiff. If she has her infusion, she helps me move her around, and she can get her legs in the car." At a recent infusion, Lilly, depressed and exhausted from the procedure, turned to her mother and said, "I quit."

"You can't quit!" Gay told her daughter. "There is no quitting."

Gay understands and is humbled by her daughter's spirit. "I don't know if I could do what Lilly does. Have the smile, the energy, the gumption. She has this unbelievable sense of humor, this desire to be a part of the world, even though it's so hard for her. I can go out with my girlfriends and get away from it all. But Lilly has to deal with this all the time. Everything is hard."

### A Parent's Struggle

When you ask Gay how she manages, she will say it's just her life. It's all she knows.

"I go to the infusion center and think, 'This is my world. This is normal

for me.' And that's when it scares you. But it's not like I have a healthy kid so I know it any other way. This is going to be our life forever. So, the question is, what can we do to make our life better? We can work on our marriage. We're a team," she says. "I couldn't do this without Steve."

Though Gay has found support in unexpected places, she's been saddened by some of her friends' and sometimes even her family's inability to understand the constraints of their life. They often don't realize how hard it is for Lilly to do something without serious effort or accommodation on their part. "I guess it just happens when you cannot participate in the same family activities — skiing, sports, camping — you kind of fall off their radar screen and lose touch. Having a kid with special needs often magnifies the distance that evolves. That's the biggest disappointment from the whole experience," she says. "We often don't quite fit into the pretty picture of what is supposed to be going on."

Gay's life is a far cry from what she imagined for herself as a girl, or even at 30, when she had Lilly. "My life was planned. We knew we'd have two or three kids. My house was dec-

orated. My china pattern was complete. Everything was just the way it should be. And then I got pregnant, and what I thought was my perfect world came shattering down."

Would she have been happier than she is now, in this mythical perfect life? She can't even imagine it. "Was I ever that shallow," she wonders, to think that a nice home and healthy children are the necessary prerequisites to a happy life? Because she is happy every day that she helps create a happy day for Lilly. Every night when Lilly can go to sleep thinking happy thoughts is a night that Gay and Steve go to bed happy themselves. It's as simple as that. ■

**RACHEL MORTON** is the editor of *Emma* magazine and director of Rachel Morton Associates, a communications consulting firm in Burlington, Vt., specializing in college magazines and recruitment publications for higher education. Morton is a former trustee of CASE and a member of its Commission on Communications.

*Reprinted courtesy of Emma, the magazine of Emma Willard School, since 1814, a boarding and day school, grades 9-12, empowering girls who transform the world.*

*Photography courtesy of Max Gerber, [www.msgphoto.com](http://www.msgphoto.com)*

# Choosing Needles for IVIG and SCIG

By Kris McFalls



**PATIENTS RARELY PUT** much thought into the needle used to infuse their immune globulin (IG). In most cases, the size and brand of needles are decided by what the provider has in stock. A heightened sense of awareness about the choice of needles seems to come into play only after a patient has a problem. This is particularly the case for subcutaneous infusions (SCIG), during which the choice of supplies and the willingness to adjust can be essential to successful and comfortable therapy.

## Needle Terms

Having some basic knowledge will help patients to make a choice about which needles to use.

**Gauge.** The gauge of a needle is its thickness or diameter. The larger the number, the slimmer the bore of the needle. Larger bore needles are needed for higher flow rates and maintaining integrity of cells.

A 27-gauge needle is commonly used for SCIG. However, a 24-gauge needle is now being produced. Because IG is a very viscous fluid, it is believed that the larger bore

should decrease resistance and, it is hoped, decrease the time and alarm problems currently experienced with some current SCIG pumps.

For intravenous IG (IVIG), most nurses use a 20-, 22- or 24-gauge needle. IV needles are universally color-coded for gauge. The most common color needles for IVIG are pink for 20-gauge, blue for 22-gauge and yellow for 24-gauge.

For port-a-catheters, a 22-gauge needle is typically used, but the gauge can be different depending on what is being infused and the size of the port.

**Catheter.** A catheter is a needle with a soft sleeve. The needle is used for insertion, and then removed, leaving the catheter in place. Although catheters are more commonly used for IVIG needles, they also can be used for SCIG. When used for SCIG, the needles are available with an inserter, which allows the patient to insert the needle with the push of a button instead of manually.

**Length.** The length of the needle is listed in inches or

millimeters. For IVIG, the length is typically determined by the nurse inserting the needle. According to Kim Duff, RN, attending patients at University Hospitals, "Some nurses prefer the smaller diameter and/or gauge [either 3/4 inch or 1 inch] because it is believed to cause less scar tissue to the inner vein."

For SCIG, the length is determined by the patient's amount of subcutaneous (fat) tissue. Depending on the manufacturer, needle lengths come in 4, 6, 9, 12 and 14 mm, and size matters! A needle that is too long can be pushed into muscle tissue, causing a painful infusion, while a needle that is too short can cause leaking. In addition, the tubing attached to the needle can come in different lengths. Longer tubing allows more flexibility for infusing at sites further apart. Shorter tubing may be preferred for pediatric patients.

The length of port-a-catheters varies, depending on the depth of the port and the amount of tissue over the port.

### Needle Use

"Once a needle is placed, an infusion should not hurt," explains Nancy Creadon, RN, vice president of VaxAmerica, a subsidiary of NuFACTOR, the specialty pharmacy of FFF Enterprises, Inc. If there is pain during a peripheral infusion, the catheter needs to be replaced. If the infusion sites are painful during SCIG, patients may need to check with their nurse or pharmacist regarding how to adjust the needle length or placement.

While many factors go into choosing needles, ease of use and comfort during infusion are what will determine how successful treatment will be. ■

**KRIS MCFALLS** is IG Living's patient advocate.

## Directory of SCIG Needles



### eMedicalDevices

The family of Safety SCIG multi-needle infusion therapy products for pediatric and adult patients features ultra-flexible polyethylene tubing; a 27-gauge needle (available in 6 mm to minimize patient trauma or 9 mm for patients with thicker

skin); optimized needle contour curvature to ensure maximum flow through the needle; and a translucent wing to facilitate insertion and provide stability for long-term use. Hypoallergenic dressings are included with each needle site for ease of placement. Special accessories ensure compatibility with all major ambulatory infusion pumps. Special connectors, accessories or design adaptations are available for specific infusion pumps.

**(888) 550-6500;**

**[emedicaldevices.com/scig-infusion-sets-s.html](http://emedicaldevices.com/scig-infusion-sets-s.html)**



### IntraPump

Neria Detach is a single-line infusion set that disconnects at a separate site, providing extra security and comfort. It has a 90-degree

angled needle for easy insertion and a pre-attached adhesive. Neria Detach is made from skin-friendly latex-free tubing, which reduces the risk of contact allergies commonly associated with tubing from polyvinylchloride. Infusion is still performed on multiple sites in the same period of time, just one site at a time, reducing problems with site absorption and drug waste in long tubing, and eliminating the need to search for multi-tubing occlusion issues. And, tubing does not need to be changed before each rate change. It comes with a standard luer lock connection, and it can be used with any standard luer lock syringe.

**(866) 211-7867; [www.intrapump.com](http://www.intrapump.com)**

## MarCal Medical



MarCal's Sub Q and Safety Sub Q right-angle needle infusion sets feature easier needle insertion and flexible wings for optimum viewing of insertion site; integrated wings on the needle to lay flat against the skin; and central position of the needle for stability and comfort. A variety of needle lengths and gauges are available (24- and 27-gauge, 6 mm, 9 mm, 12 mm and 14 mm), and specialty gauges and needle lengths are available. Sets come with colored side clamps for easy identification for pull pack on each site, and transparent dressing is included in a sterile package.

**(800) 628-9214;**

**[www.marcalmedical.com/subQsafetySubQ.htm](http://www.marcalmedical.com/subQsafetySubQ.htm)**



## Medtronic

Medtronic Sof-set QR was originally designed for insulin therapy. The Sof-set needle is inserted with the Sof-serter device at the press of a

button, making insertions quick, easy and virtually painless. With the Sof-set, a soft cannula is all that remains in place. A special adhesive dressing inhibits bacterial growth.

**(866) 948-6633; [www.minimed.com](http://www.minimed.com)**



## Norfolk Medical

Norfolk provides a complete line of SCIG infusion sets and extension sets. The infusion sets feature two,

three, four or five lumens that each have 36-inch microbore tubing with 24-, 25- or 27-gauge needles. There is a transparent clear disk with adhesive on each disk for placement stability. Needle lengths can be modified to 4 mm, 6 mm, 9 mm and 12 mm. Custom sets can be created to fit specific needs. Extension sets come without needles and feature 20-inch microbore tubing attached to two, three, four or five lumens, and allow for patients to use the needle set of their choice. A subcutaneous infusion set must be added to each extension set and connected to the luer lock connection. Six sets come in each box.

**(847) 674-7075;**

**[www.norfolkmedical.com/IVIG%20delivery%20sets.html](http://www.norfolkmedical.com/IVIG%20delivery%20sets.html)**



## RMS Medical

RMS Medical's new Daisy Chain Needle Set connects to as many sites as needed and is engineered for maximum flow. Each needle adjusts to 6 mm, 9 mm and 12 mm lengths. The set

eliminates the need for bi, tri and quad sets. Adhesive wings attach to the patient and come together after use to prevent needle stick injury.

**(845) 469-2042;**

**[www.rmsmedicalproducts.com/administrationsets.htm](http://www.rmsmedicalproducts.com/administrationsets.htm)**

For a more comprehensive list of resources, visit the Resources page at [www.IGLiving.com](http://www.IGLiving.com).

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## Ataxia Telangiectasia (A-T)

### Websites

- A-T Children's Project: [www.atcp.org](http://www.atcp.org)

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## Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

### Websites

- GBS/CIDP Foundation International: [www.gbs-cidp.org](http://www.gbs-cidp.org)
- The Neuropathy Association: [www.neuropathy.org](http://www.neuropathy.org)

### Online Peer Support

- Barbara's CIDP/GBS Site: [www.geocities.com/HotSprings/Falls/3420](http://www.geocities.com/HotSprings/Falls/3420)

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## Evans Syndrome

### Online Peer Support

- Evans Syndrome Research and Support Group: [www.evanssyndrome.net](http://www.evanssyndrome.net)

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## Guillain-Barré Syndrome (GBS)

### Websites

- GBS/CIDP Foundation International: [www.gbs-cidp.org](http://www.gbs-cidp.org)
- The Neuropathy Association: [www.neuropathy.org](http://www.neuropathy.org)

### Online Peer Support

- GBS & CIDP Discussion Forum – UK Bulletin Board (For Ireland and England): [www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi](http://www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi)
- GBS/CIDP Foundation International Discussion Forums: [www.gbs-cidp.org/forums](http://www.gbs-cidp.org/forums)
- GBS Support Group and Chat Room – UK: [www.jsmarcussen.com/gbs/uk/chat.htm](http://www.jsmarcussen.com/gbs/uk/chat.htm)

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## Idiopathic Thrombocytopenic Purpura (ITP)

### Websites

- ITP Support Association – UK: [www.itpsupport.org.uk](http://www.itpsupport.org.uk)
- National Heart, Lung and Blood Institute: [www.nhlbi.nih.gov/health/dci/Diseases/Itip/ITP\\_WhatIs.html](http://www.nhlbi.nih.gov/health/dci/Diseases/Itip/ITP_WhatIs.html)
- Platelet Disorder Support Association: [www.pdsa.org](http://www.pdsa.org)

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## Kawasaki Disease

### Websites

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

- Kawasaki Disease Foundation: [www.kdfoundation.org](http://www.kdfoundation.org)
- KidsHealth: <http://kidshealth.org/parent/medical/heart/kawasaki.html>

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## Mitochondrial Disease

### Websites

- United Mitochondrial Disease Foundation: [www.umdf.org](http://www.umdf.org)

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## Multifocal Motor Neuropathy (MMN)

### Websites

- The Neuromuscular Center at Washington University: [www.neuro.wustl.edu/neuromuscular](http://www.neuro.wustl.edu/neuromuscular)
- The Neuropathy Association: [www.neuropathy.org](http://www.neuropathy.org)

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## Multiple Sclerosis (MS)

### Websites

- All About Multiple Sclerosis: [www.mult-sclerosis.org/index.html](http://www.mult-sclerosis.org/index.html)
- Multiple Sclerosis Association of America: [www.msaa.com](http://www.msaa.com)
- Multiple Sclerosis Foundation: [www.msfacts.org](http://www.msfacts.org)
- National Multiple Sclerosis Society: [www.nationalmssociety.org](http://www.nationalmssociety.org)

### Online Peer Support

- Friends with MS: [www.FriendsWithMS.com](http://www.FriendsWithMS.com)
- MSWorld's Chat and Message Board: [www.msworld.org](http://www.msworld.org)

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## Myasthenia Gravis (MG)

### Websites and Chat Rooms

- Myasthenia Gravis Foundation of America (MGFA): [www.myasthenia.org](http://www.myasthenia.org)

### Online Peer Support

- Autoimmune Information Network Inc.: [www.aininc.org](http://www.aininc.org)

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## Myositis

### Websites

 <p>THE MYOSITIS ASSOCIATION</p>	<p>The mission of The Myositis Association, <a href="http://www.myositis.org">www.myositis.org</a>, is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. (202) 887-0088</p>
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- International Myositis Assessment and Clinical Studies Group: <https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main>
- The Cure JM Foundation: [curejm.com](http://curejm.com)

## Online Peer Support

- Juvenile Myositis Family Support Network: [www.curejm.com/family\\_support/index.htm](http://www.curejm.com/family_support/index.htm)
- Myositis Association Community Forum: [www.myositis.org](http://www.myositis.org)
- Myositis Support Group: [www.myositissupportgroup.org](http://www.myositissupportgroup.org)
- Myositis Support Group – UK: [www.myositis.org.uk](http://www.myositis.org.uk)

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## Pemphigus and Pemphigoid

### Websites

- The International Pemphigus and Pemphigoid Foundation: [www.pemphigus.org](http://www.pemphigus.org)

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## Peripheral Neuropathy (PN)

### Websites

 <p><b>The Neuropathy Association</b></p>	<p>The Neuropathy Association, <a href="http://www.neuropathy.org">www.neuropathy.org</a>, is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association's mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, advocate the need for early intervention and support research into the causes and treatment of neuropathies. (212) 692-0662</p>
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- Neuropathy Action Foundation: [www.neuropathyaction.org](http://www.neuropathyaction.org)

### Online Peer Support

- Calgary Neuropathy Support Group: [www.calgarypnrs.org](http://www.calgarypnrs.org)

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## Primary Immune Deficiency Disease (PID)

### Websites

	<p>The Immune Deficiency Foundation (IDF), <a href="http://www.primaryimmune.org">www.primaryimmune.org</a>, 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</p>
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### Jeffrey Modell **jm** Foundation

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

- The National Institute of Child Health and Human Development (NICHD), [www.nichd.nih.gov](http://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.aaaaa.org](http://www.aaaaa.org)
- International Patient Organization for Primary Immunodeficiencies (IPOPI): [www.ipopi.org](http://www.ipopi.org)
- Michigan Immunodeficiency Foundation: [www.midf.org](http://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](http://www.nichd.nih.gov))
- New England Primary Immunodeficiency Network: [www.nepin.org](http://www.nepin.org)
- Rainbow Allergy-Immunology: [www.rainbowbabies.org/immunology](http://www.rainbowbabies.org/immunology)
- Team Hope (for families and patients in New England): [www.teamhope.info](http://www.teamhope.info)

### Online Peer Support

- IDF Common Ground: [www.idfcommonground.org](http://www.idfcommonground.org)
- IDF Discussion Forum: [my.primaryimmune.org/forum](http://my.primaryimmune.org/forum)
- IDF Friends: [www.idffriends.org](http://www.idffriends.org)
- Jeffrey Modell Foundation Message Board: [www.info4pi.org](http://www.info4pi.org)
- Rhode Island peer group: <http://health.groups.yahoo.com/group/RhodeIslandPIDD>

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## Scleroderma

### Websites

**Scleroderma Center:** <http://scleroderma.jhmi.edu>

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

### Online Peer Support

- CureZone.com: [curezone.com/forums/f.asp?f=404](http://curezone.com/forums/f.asp?f=404)
- International Scleroderma Network: [www.sclero.org/support/forums/a-to-z.html](http://www.sclero.org/support/forums/a-to-z.html)

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## Stiff-Person Syndrome (SPS)

### Websites

- American Autoimmune Related Diseases Association Inc.: [www.aarda.org](http://www.aarda.org)
- Autoimmune Information Network Inc.: [www.aininc.org](http://www.aininc.org)
- Living with Stiff Person Syndrome (personal account): [www.livingwithsps.com](http://www.livingwithsps.com)

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## 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](http://www.advocacyforpatients.org)
- Alliance for Plasma Therapies (fair access to plasma therapies): [www.plasmaalliance.org](http://www.plasmaalliance.org)
- American Autoimmune Related Diseases Association (AARDA): [www.aarda.org](http://www.aarda.org)
- American Chronic Pain Association (ACPA): [www.theacpa.org](http://www.theacpa.org)
- Band-Aides and Blackboards: [www.lehman.cuny.edu/faculty/jfleitas/bandaides](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides)
- Cleveland Clinic: [www.clevelandclinic.org/health](http://www.clevelandclinic.org/health)
- eMedicine from WebMD: [emedicine.medscape.com](http://emedicine.medscape.com)
- FamilyDoctor.org: [www.familydoctor.org](http://www.familydoctor.org)
- Johns Hopkins Medicine: [www.hopkinsmedicine.org](http://www.hopkinsmedicine.org)

- KeepKidsHealthy.com (pediatrician's guide to children health and safety): [www.keepkidshealthy.com](http://www.keepkidshealthy.com).
- Kids Health (medical and emotional impact of caring for an ill child): [www.kidshealth.org/parent/system/ill/seriously\\_ill.html](http://www.kidshealth.org/parent/system/ill/seriously_ill.html)
- Mayo Clinic: [www.mayoclinic.com](http://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](http://www.ncqa.org).
- National Institute of Neurological Disorders and Stroke (NINDS): [www.ninds.nih.gov/disorders/disorder\\_index.htm](http://www.ninds.nih.gov/disorders/disorder_index.htm)
- National Institutes of Health: [www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm](http://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](http://www.rarediseases.org)
- Office of Rare Diseases Research: [rarediseases.info.nih.gov](http://rarediseases.info.nih.gov)
- Patient Advocate Foundation (patient access to care, maintenance of employment and financial stability): [www.patientadvocate.org](http://www.patientadvocate.org)

	<p>The nonprofit Patient Services Incorporated, <a href="http://www.needpsi.org">www.needpsi.org</a>, specializes in health insurance premium, pharmacy co-payment and co-payment waiver assistance for people with chronic illnesses. (800) 366-7741</p>
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- WebMD (medical reference): [www.webmd.com](http://www.webmd.com)

### Education and Disability Resources

- Americans with Disabilities Act of 1990: [www.ada.gov](http://www.ada.gov)  
Provides protection for people with disabilities from certain types of discrimination, and requires employers to provide some accommodations of the disability.
- Continuation of Health Coverage — Consolidated Omnibus Budget Reconciliation Act (COBRA): [www.dol.gov/dol/topic/health-plans/cobra.htm](http://www.dol.gov/dol/topic/health-plans/cobra.htm)
- DisabilityInfo.gov: [www.disabilityinfo.gov](http://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.ndrn.org](http://www.ndrn.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](http://www.ssa.gov/disability)
- U.S. Department of Education Website: [www.ed.gov](http://www.ed.gov)  
This federal government website offers a parents section titled "My Child's Special Needs."
- U.S. Department of Health and Human Services, Office of Civil Rights: [www.hhs.gov/ocr/office/news/2008/discrimdisab.html](http://www.hhs.gov/ocr/office/news/2008/discrimdisab.html)  
Spells out your rights under Section 504 of the Rehabilitation Act.

### Medical Research Studies

- ClinicalTrials.com: [www.clinicaltrials.com](http://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](http://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](http://www.aaaai.org)
- American Partnership for Eosinophilic Disorders: [www.apfed.org](http://www.apfed.org)
- Food Allergy and Anaphylaxis Network: [www.foodallergy.org](http://www.foodallergy.org)
- National Institutes of Health, National Institute of Allergy and Infectious Diseases (2004). Food Allergy: An Overview (NIH Publication No. 04-5518): [www.niaid.nih.gov/publications/pdf/foodallergy.pdf](http://www.niaid.nih.gov/publications/pdf/foodallergy.pdf)
- Sicherer, S.H. (2006). "The Complete Peanut Allergy Handbook: Understanding and Managing Your Child's Food Allergies," Johns Hopkins Press.
- World Allergy Organization: [www.worldallergy.org](http://www.worldallergy.org)

### Product Information

- Influenza and the influenza vaccine: [www.cdc.gov/flu](http://www.cdc.gov/flu) or call (800) CDC-INFO: (800) 232-4636
- IVIG Carimune NF: [www.carimune.com](http://www.carimune.com)
- IVIG Flebogamma: [www.grifolsusa.com/pdfs/flebo\\_14Jun05.pdf](http://www.grifolsusa.com/pdfs/flebo_14Jun05.pdf)
- IVIG Gammagard Liquid: [www.gammagardliquid.com](http://www.gammagardliquid.com)
- IVIG Gammagard S/D: [www.immunedisease.com](http://www.immunedisease.com)
- IVIG Gamunex: [www.gamunex.com](http://www.gamunex.com)
- IVIG Octagam: [www.octapharma.com](http://www.octapharma.com)
- IVIG Privigen: [www.privigen.com](http://www.privigen.com)
- SCIG (subcutaneous immune globulin) Vivaglobin: [www.vivaglobin.com](http://www.vivaglobin.com)

### IG Manufacturer Websites

- Baxter: [www.baxter.com](http://www.baxter.com)
- CSL Behring: [www.cslbehring.com](http://www.cslbehring.com)
- Grifols: [www.grifolsusa.com](http://www.grifolsusa.com)
- Octapharma: [www.octapharma.com](http://www.octapharma.com)
- Talecris: [www.talecris.com](http://www.talecris.com)

### Pump and Infusion Sets Websites

- EMED Corporation: [www.safetymedicalproducts.com](http://www.safetymedicalproducts.com)
- Graseby Marcal Medical: [www.marcalmedical.com](http://www.marcalmedical.com)
- Intra Pump Infusion Systems: [www.intrapump.com](http://www.intrapump.com)
- Micrel Medical Devices: [www.micrelmed.com](http://www.micrelmed.com)
- Norfolk Medical: [www.norfolkmedical.com](http://www.norfolkmedical.com)
- Repro Med Systems, Inc: [www.rmsmedicalproducts.com](http://www.rmsmedicalproducts.com)
- Smith Medical: [www.smiths-medical.com/brands/cadd](http://www.smiths-medical.com/brands/cadd)

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*Have something to add to these pages? Please send your suggestions for additions to the IG Living Resource Directory to [editor@IGLiving.com](mailto:editor@IGLiving.com).*

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