

# IG LIVING!

IMMUNE GLOBULIN COMMUNITY

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February-March 2006



## **How Safe Is the U.S. Pharmaceutical Supply Channel? And Why You Should Care!**

On Your Own: Transitioning Teens

Reimbursement Matters:  
Medicare and Immune Globulin

A community service from FFF Enterprises and NuFACTOR, its specialty pharmacy services division

**ACTION ALERT: Call your Member of Congress today to protect IG access!**

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### About IG Living

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

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# Yoo Hoo! Is Anybody Out There?



We think so! We've heard their voices—some frightened, seeking a doctor to give definition to their symptoms; some confident, knowing that their disease is manageable; some lonely, hungry for camaraderie; some enthusiastic, eager to share what they have learned; some distraught, blindsided by a child's diagnosis; some relieved, joyful in the recognition of others with common experience.

Yes, we think there are many of you out there, people across the country—all ages, all races, all walks of life—who, together, form the community of people who use immune globulin. You infuse this miracle plasma product to boost your immune systems, to recover from pain or paralysis, to remain healthy, active members of a vital community.

You are living with myositis, a peripheral neuropathy, a primary immune deficiency, Guillain-Barré syndrome—or caring for someone who does. You are frightened, you are creative, you are living with loved ones, you are on your own, you are struggling, you are exploring, you are searching for insight, looking for companionship, offering support.

And that is why *IG Living* is here: to help you find each other, learn from one another and from healthcare professionals, contemplate new ideas and possibilities, and, in the process, make your life a little easier.

In this, our first issue, you will hear the voices of this wide and wonderfully varied group of people out there.

Shirley Vulpe, an occupational therapist and patient, explains the basics of immune globulin therapy.

You can pick up some great travel tips from Carol Milette, who uses them to help manage her primary immune deficiency and her professional life.

Alma Morales reports that recent Medicare reimbursement rate reductions for immune globulin can have a ripple effect throughout the health insurance industry.

You'll laugh with Cheryl Haggard as she recounts her wild ER adventure with her sick child and ESPN-distracted husband.

Emily Pulley's story about transitioning teens confirms that children with chronic diseases can indeed successfully spread their wings and fly from the nest.

You'll learn about peripheral neuropathy from Angela Macropoulos, a whirlwind who practices law, goes to school and cares for her mother, who has a peripheral neuropathy.

Dan Bennett's story on intravenous immune globulin is the first in a series of three about immune globulin administration methods.

An interview with author Katherine Eban reveals the dark side of the U.S. pharmaceutical distribution channel.

An article from The Neuropathy Association tells the story of a real superwoman who chose the Ironman triathlon as her response to being diagnosed with Parsonage-Turner syndrome, a rare neuropathy.

You'll find a wonderful introduction to the concept of resilience as a tool for managing chronic illness in a piece by Reginald Nettles, PhD, a psychologist who has X-linked agammaglobulinemia.

The mother of three young children with primary immune deficiency disease, Dayna Fladhammer, assures other parents in her column that they are not alone.

Yes, we know there are many of you out there—and that it can sometimes be lonely or scary, but there are places where you can connect with your community; where you can become better informed about immune globulin therapy; where you can be reassured by people who know what you're going through; where you can learn from others and, in turn, make them feel at home. We hope this magazine will provide that haven, that potbelly stove in the general store, where you can kick back in your favorite chair, surrounded by kindred souls, and have a darn good chat about *IG Living*!

If you like the idea of *IG Living*, if you want to share in the fun, the comfort, the discussion, the "ah ha!" moments, sign up for your free subscription at [www.igliving.com](http://www.igliving.com) or fill out and mail the subscription card insert.

And, if you have ideas about what will make us an even better gathering spot, please let us know. Email us at [editor@igliving.com](mailto:editor@igliving.com). ■

Kit-Bacon Gressitt, Editor

# REIMBURSEMENT MATTERS

## Medicare and Immune Globulin

By Alma Lucy Morales

When Linda Swim had to wait nearly two months for her routine treatment of immune globulin, and her doctor's office was forced to postpone her regular treatments, she knew her condition would worsen. Previously, Swim's life had significantly improved since she had started immune globulin therapy in 1996, and she feared what would happen if she were unable to obtain her scheduled infusions. "Before I began my IVIG treatments, my condition was so severe that I was in bed all the time. I was so weak that I could not get out of bed except to go to the bathroom. I had to stop working. I could not do anything for myself. It was terrible."

Swim's situation is an example of how changes in Medicare reimbursement for the administration of immune globulin have unintentionally jeopardized the health of patients who rely on this lifesaving therapy.

According to the Centers for Medicare & Medicaid Services (CMS), the Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA) was created to "modernize the Medicare program" and improve access to care. In theory, the MMA was supposed to save tax dollars while allowing those in need to receive proper treatment. In practice, however, in many cases, patients have been denied care in their traditional settings. The reason is purely economic.

The January 1, 2005, congressionally mandated reduction in Medicare Part B reimbursement rates and the two-tier rates for liquid and lyophilized (powdered) immune globulin, implemented on April 1, 2005, established two different rates for administering immune globulin to patients, depending on where the treatment is received: in the physician office and at home or in the hospital outpatient setting. The new reimbursement methodology significantly lowered the rate paid to physician offices and homecare companies for immune globulin infusions—at a time when immune globulin prices were rising and supplies of immune globulin products were tightening.

The combination of reduced reimbursement, rising prices and tightening supply created a dangerous situation



in which seriously ill, low-income patients with primary immune deficiencies or neuropathies were struggling to maintain access to care. In many cases they were unable to access treatment, causing their health to deteriorate.

By May of 2005, the reduced rate at which physicians' offices were being reimbursed was so devastating that many physicians had no choice but to refer their patients elsewhere. These patients had to resort to receiving treatment in a hospital, where their co-pays were as high as \$649 per treatment and their exposure to infection was increased.

"It is an intolerable position to be in, when we cannot receive reimbursement for the services we have provided for our patients, reimbursement that will allow us to at least cover our own cost for the products administered. All of us at our office simply want to care for our patients in a compassionate and effective manner, and not be forced into positions that compromise our quality of patient care and the health of the people we serve!" said Dr. Robert Dracker of Syracuse, New York.

What many people predicted as the worst-case scenario happened in September 2005 when one patient who was unable to receive his regular immune globulin treatments died. Although Lawrence Michalski's official cause of death was cardiorespiratory disease, some doctors believe the inability to receive routine immune globulin therapy contributed to his death.

"The predictable consequences of the Medicare Modernization Act and the Part B rate reduction are due

to the unique nature of the human plasma products market and a lack of policymakers' understanding of product supply dynamics," said Patrick M. Schmidt, president and CEO of FFF Enterprises, the nation's largest distributor of immune globulin.

In this critical life-and-death environment, while Congress continues to make decisions about reimbursement, industry, patient advocacy organizations and healthcare professionals strive to improve future reimbursement decisions for the benefit of the patients.

### Working Toward a Solution

"The industry has come together to work toward a solution to the current problems with reimbursement," said Schmidt. The newly formed group comprises most of the industry's major constituents, including the Immune Deficiency Foundation, the Jeffrey Modell Foundation, The Neuropathy Association, primary channel distributors, such as FFF Enterprises, and immune globulin manufacturers, such as Baxter, Grifols, Octapharma, Talecris and ZLB Behring. The group is also working closely with the Plasma Protein Therapeutics Association, as, together, they are addressing immune globulin issues and building awareness about these issues in Congress and at CMS. "There is no easy or quick fix," Schmidt explained, "but we are working together to find a way to make things better for patients."

Educating Congress on the importance of immune globulin access for patients with primary immune diseases and neuropathies is the primary focus for this group. The combined forces are also researching legislation that can affect access to care for immune globulin consumers.

An encouraging development occurred in November 2005 when CMS responded to the need for a change in the reimbursement rates in the hospital outpatient setting. CMS established an add-on payment to cover the additional preadministration-related services required to locate and acquire adequate immune globulin product and prepare for an infusion of immune globulin in outpatient settings and physician practices. While this change temporarily addresses the issue for some patients, reimbursement for the homecare setting still needs adjustment—and the add-on is only temporary.

This series of reimbursement changes is believed by many to be likely to cause unforeseen repercussions throughout the community of immune globulin users, regardless of their health insurance provider. Because private insurers typically follow Medicare's lead, the reduction in Medicare reimbursement will likely impact private pay patients who depend on immune globulin infusions. In fact, private insurance changes have already

occurred: Two of the nation's largest private insurance companies dropped their immune globulin reimbursement rates by nearly 20 percent within the last year, and industry watchers expect other companies to follow suit.

### What You Can Do to Help

A leading organization for people with primary immune deficiencies, the Immune Deficiency Foundation (IDF), encourages immune globulin consumers to become advocates in the effort to inform Congress about the challenges of reimbursement and access to care. "Visit your local Congress members' offices and let them know how these changes have affected you," recommends Michelle Vogel, director of government affairs for IDF. "It is important for patients to share their stories with their representatives and to let them know how changes in reimbursement impact the entire immune globulin community."

Patients and national patient advocacy groups have played a key role in the improvements that have been made to reimbursement rates so far. "Putting a face on primary immune deficiency and neuropathy patients has been a driving force for Congress to get involved," says Vogel.

In recent months patient advocacy has clearly begun to have a positive effect. Representatives Jim McCrery (LA) and Steve Israel (NY), upon learning from patients about how the reimbursement reductions were impacting their quality of care, spearheaded an effort to build awareness of the importance of having access to immune globulin. The effort is ongoing and will likely become more successful as additional U.S. representatives and senators get involved.

The chain of events since the first Medicare rate reductions demonstrates that consumers can make a difference in the congressional decision-making process by simply getting involved. Calling on your U.S. senators and representatives' offices, writing letters to them, and participating in patient advocacy groups are just a few of the ways you can make a difference in the future of reimbursement and access to immune globulin therapy. As Michelle Vogel advises, let your voice be heard; you can be part of the solution! ■

#### Get Involved Today!

Contact your representative by visiting the U.S. House of Representatives website and entering your state and zip code at <http://www.house.gov/writerep/>

Find tips for contacting your senator or representative by visiting <http://www.congress.org/congressorg/issues/basics/?style=comm>

# Immune Globulin Administration: You Have Options

By Dan Bennett

This is the first of three stories detailing the three methods of immune globulin administration. In this series, patients and physicians with varying experiences and opinions will share those with readers. No particular method of administration is recommended in this series, as patients should consult their physicians to determine the best method for their particular needs.



When Jacqueline De Vries was diagnosed with common variable immunodeficiency a little more than 10 years ago, she knew she would rely in part on the strength of her family to cope. What she didn't know was that her sister Yvonne would soon require that same strength.

"I was adult-onset, developing symptoms around age 33," said Jacqueline, a Victorville, Calif., resident. "The doctors could never find the right antibiotic for me. Then one day I was rushed to the hospital because I couldn't breathe. Eight months later I was finally diagnosed, and they started me on gamma globulin. Eventually, I started living an active life again."

Yvonne had been sick much of her life. After Jacqueline was diagnosed, their mother suggested Yvonne have the same medical tests her sister did.

"Now she gets her dose every three weeks, and I get my dose every four," Jacqueline said.

Those doses are presently administered intravenously (IV), one of the three methods commonly used by immune globulin consumers. Besides IV, there is the related port method and the more recent arrival—subcutaneous—for which the FDA recently approved a product. Using the subcutaneous method—or the popular shorthand "SubQ"—the immune globulin is self-administered under the skin. It is sometimes recommended when vein access is consistently difficult or adverse side effects from IV administration occur. This method is already approved in Europe and enjoys popularity there.

For many patients, however, IVIG is a longstanding choice for administration. With IVIG, patients receive an intravenous supply of immune globulin, the dosage depending on the patient's particular needs and body weight. Often, the physician will administer varying doses until the proper amount is found. While the subcutaneous method is gaining popularity, boosted by the recent FDA approval, IVIG remains the method most often practiced. In this method, a needle attached to tubing is inserted into a vein, through which the immune globulin is infused.

*Using IV administration, patients often have the choice between treatment in a medical office or hospital and at home.*

"I never looked at my job as making the choice for the patient," said Dr. Richard Schiff, Global Medical Director for Immune Therapy at Baxter Bioscience, and a leading authority on the subject. "I've always told patients the different risks and benefits. Having said that, I also tell them what I think of the choices they have made."

Schiff explains the IVIG method to patients, also the risks and possible advantages of using a port method, wherein a permanent point of entry is established.

"Some patients are very aware of the different choices, others are not," he said. "Patients need to go into their pediatricians' offices, their internists' offices, and get all the information they can. The choice often depends on what the goal is."

Using IV administration, patients

often have the choice between treatment in a medical office or hospital, and homecare treatment. In homecare treatment, a nurse visits to administer the transfusion, and remains to monitor any possible side effects. Family members also help monitor the patient, and the patient takes a more active role in the treatment.

Jacqueline spent almost a year visiting a hospital for her treatment, but then switched to homecare.

"That change wasn't difficult for me," Jacqueline said. "For some people, I've heard it can be difficult if there are insurance issues or if the doctor wants to maintain more control over the patient. But I found it so much easier to do at home. I was able to find an excellent nurse to help me, I had more freedom to set the time for the treatment, and I feel like that by

having the treatment at home, I'm warding off some of the risk of infection that might be present if I'm going to a hospital chemo room for my treatment. Also, the one-on-one interaction is nice."

After she was diagnosed, Jacqueline said the first year was the most challenging. "I had to learn what my body could take," she said. "I had to develop my own style, and learned the best pace for my infusion, that if I took the infusion at a certain rate, I would get headaches. Now my body has taught me how to do this, and I'm feeling so much better!" ■

*In the April-May 2006 issue of IG Living, we will explore subcutaneous administration of immune globulin.*



# Shands at Old Oak\*

By Cheryl Haggard

Everything was going fine until the unrelenting screaming forced Mark and me to make the 15-minute trip to the emergency room in Old Oak, Florida. We had been heading to Disney World for the Immune Deficiency Foundation's convention, when a routine dip in a hotel pool went devastatingly wrong for our daughter, Molly. She got pool water in one of her ear tubes, and we feared the tube might have dislodged and she probably had an infection. If one trip to the ER was all we had in store, we were doing pretty well.

Shands Hospital in Old Oak, Florida, is about what I expected it to look like: a glorified convalescent hospital with mint green walls and the stench of disinfectant stinging my nostrils. As I approached the check-in desk, the pear-shaped security guard, with her bleached blond hair neatly pulled back into a ponytail, greeted me with a toothless grin. Her profound Southern drawl announced to me, "Welcome to my nightmare."

I signed Molly in and pushed the little red button that alerted the nurse (probably hiding from the patients was my guess) that there was a new patient waiting.

Holding Molly fast, we stood in the corner of the room as I felt the eyes of the waiting room fraternity glare at me. It was obvious that we were foreigners: I forgot to check our "Idaho—Famous Potatoes" license plates at the door.

With caution, I inspected the waiting room at Shands of Old Oak.

There was a middle-aged man sitting in a wheelchair holding his ring finger with gauze, so as not to drip blood on the tile floor. His well-groomed wife with her beehive up-do gossiped with the elderly woman next to her. A toddler, cranky and hyper with fatigue, as the hour was late, jumped from Naugahyde chair to Naugahyde chair; his exasperated father slumped over with exhaustion. Finally, a group of bored teens gleefully watched "Roseanne" on the small, dusty TV. I decided to stay put, far away from the motley crew that I am sure all had some good reason for being there.

"Molly Grace Haggard," bellowed the nurse from the musty hallway.

"Finally!" I muttered under my hot breath.

Our nurse, full-figured and sweaty from the Florida humidity, escorted us to the triage room where the

questions of Molly's condition began peppering us. Fearing the impatient group that was wall-shot away, I kindly requested under my breath if there was another room we could wait in as not to aggravate Molly's immune disorder or the savages in the official waiting room.

"Shouldn't be a problem. I understand," the Southern woman quipped. "Yah, we had a good ol'-fashioned barroom brawl jus' a while ago. Some of the patients didn't like our hospital rule about takin' child'n first. I'll see if the radiation room is clean fo' ya'll."

I didn't know what was more dangerous to our health at the time: exposing my child to radiation or the angry Floridian mob. I voted for radiation.

Our custom waiting corner was a pleasant surprise. It was nicely carpeted and well-stocked with books and magazines, and even a few crayons and coloring books for Molly. The coup de grâce was the television carefully situated on a wall hanger, calling out to my husband, "ESPN, ESPN, ESPN!"

My moments of quiet and safety were about to be interrupted, however.

"Wha's wrong with yo' baby?" a middle-aged woman from the waiting room fraternity asked, interrupting my peaceful peek at a 3-month-old magazine. It was the Beehive Gossip.

I was a little afraid that she was going to hurt me upon finding out Molly had a simple earache. I better be nice to this woman, I thought to myself. So I decided to engage in a conversation with the Beehive that, unbeknownst to me at the time, would change my life forever.

"Our daughter has an immune disorder, and we think she has an ear infection. She might have blown out her ear tube, as well."

With Southern sympathy she answered, "Po' baby! Those ear things hurt real bad!"

"Yeah. She'll be OK," I replied. "Thanks for your concern."

An angelic smile took the place of worry on the face of a woman I had judged unworthy of my attention.

Gesturing toward the X-ray room, I asked my new best friend, "What happened to your husband?"

I had officially opened the can of worms.

"Oh that man of mine, he's an accident looking for a happenin'," her voice rising in anger. "If we ain't in here



every week, I don't know what I'd do with m'self." Her story continued. "Ya' see, he was fixin' to eat a piece of cheese, and he put the hunk in his hand. Ya' think he'd put it on the cheese block, but noooo, he had to cut the cheese right on his hand, and he sliced himself right through to the bone. That's why they are taking a picture, to make sure he didn't hurt his bone."

"Oh, I am so sorry. I am sure he will be OK," I said, trying to sound a little sympathetic. I really thought that our conversation was over, when the Beehive began speaking again.

"Ya' know, there was this one time I came in here. Ya' see, I practice witchcraft, ya' know, and I was drilling a hole through this bird. I missed the bird and drilled a hole right through my hand...ya' see, here's the scar."

I was numb.

Mark was absorbed in the NBA Finals.

The Beehive asked if I could see the scar and all I could manage was an "uh huh." I knew we were in the South, where black magic takes place, but she was so normal looking. I'd expect a witch to look kind of dark and gloomy. She was, well, motherly looking. To prevent us from being hexed, and to test if my mouth was indeed still on my face and not the floor, I asked, "Well, how many stitches did you have to get?"

"Well, that darned drill bit was so hot, I swear it cauterized my hand. I didn't have to get one stitch!"

Thankfully, her husband began walking back to the waiting room, and she left me with, "Well, hope yo'

baby gets to feelin' bet-ah." All I could do was smile and nod graciously at her. I turned to Mark, diverted his attention from the TV, and asked, "Did you hear

what that woman said?"

"Yeah," Mark answered, his eyes still glued to the tube.

"Mark, she said she practices witchcraft and was drilling a hole in a bird!!" I said with desperation in my voice.

"That's not what she said," Mark rebutted, now giving me his attention. "She said she practiced woodcraft and was drilling a hole in a board."

Our laughter filled the big empty we called paradise for 10 solid minutes. If being from Idaho wasn't bad enough, laughing for no apparent reason really caused concern for the occasional walk-through of a hospital employee.

The Beehive conversation was a needed gift that broke the stress of having a sick child on vacation in a very strange land. At that moment, laughter really was the best prescription for Molly's ear infection. The debate still goes on to this day whether or not the Beehive was a witch or a woodworker with a misguided drill. What we do know is that our trip to Shands of Old Oak was worth every penny of our co-payment.

The cost of an ear infection on vacation: \$125.00.

The cost of the antibiotic to treat the infection: \$30.00.

The cost of a good laugh at Shands of Old Oak: priceless. ■

\* Names have been changed to protect the outrageous.

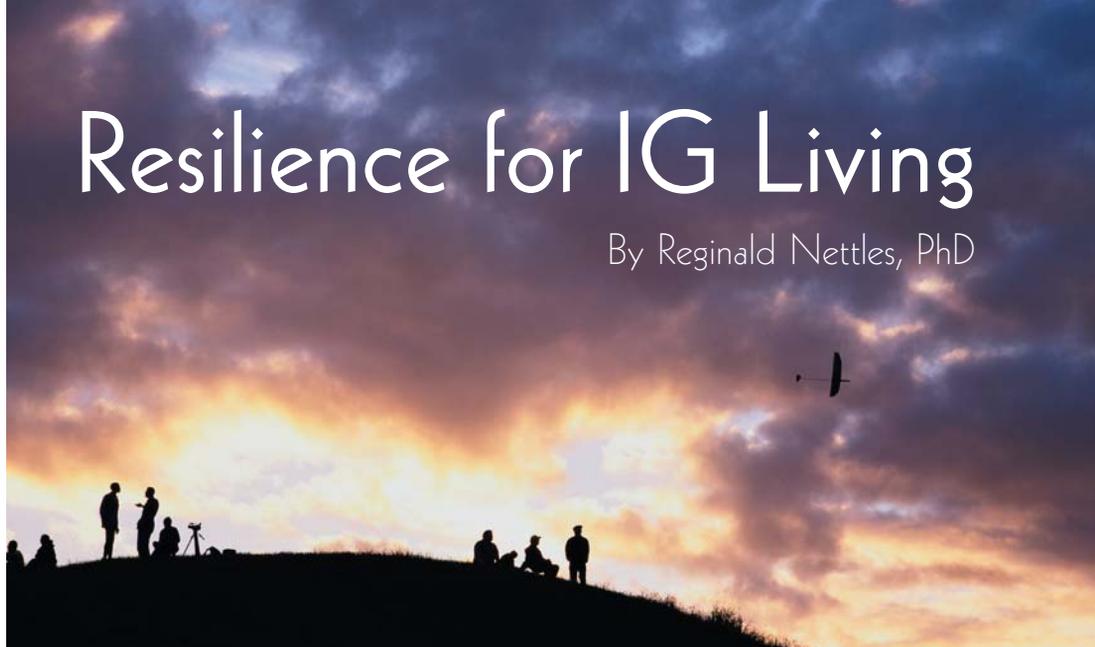
# Resilience for IG Living

By Reginald Nettles, PhD

**A**re you resilient? If you are reading this article, then chances are you have thought about it. You may be an IG patient or a parent, a caregiver or a loved one of a person who receives regular IG therapy. If so, surely you have thought about the many ups and downs of life with a chronic disorder, such as a primary immune deficiency disease (PIDD), neuropathy or myositis. (Primary immune deficiency diseases are caused by inherited defects in the cells or tissues of the immune system, and there are also acquired immune deficiencies.) Effective treatment of such disorders requires state-of-the-art medical care, provided by primary care physicians and immunologists knowledgeable about these diseases, and the gold standard of care, intravenous immune globulin therapy. Coping with the emotional and psychosocial impacts of these disorders requires resilience. Resilience is the capacity to bounce back from trauma, adversity or significant stressors, such as chronic, life-threatening illness. Resilience cannot be infused intravenously, but it can be learned.

Advances in treatment of PIDD and other disorders have progressed exponentially as a result of research over the past 20 years. However, little has been written about the challenges of coping with the emotional and psychological aspects of life with disorders requiring IG therapy and the complexities of their treatment. Resilience provides a model set of strategies for coping with chronic and, at times, overwhelming stress. Not to be confused with “feel good” approaches to wellness that deny the reality of genuine human suffering, resilience involves facing the realities of adversity and the painful emotions that often result. Rather than denying these realities, resilience involves facing them, with the tools needed to deal with them effectively.

Following the traumatic events of September 11, 2001, the American Psychological Association (APA) initiated a nationwide campaign to inform the public about resilience in the lives of ordinary people facing extraordinary events.\*



## Key Factors in Resilience

- Caring and supportive relationships within and outside the family
- The capacity to make realistic plans and take steps to carry them out
- A positive view of yourself and confidence in your strengths and abilities
- Skills in communication and problem solving
- The capacity to manage strong feelings and impulses

Resilience is a process of adapting to adversity. It is not a trait that some people are born with and others are not. Resilience can be learned. This process is part of the lifelong journey, involving different adaptations and strategies throughout the life span. Each stage of life with a chronic illness presents its own set of challenges. Whether you are a middle-aged working adult who has to reduce working hours or consider early retirement to cope with fatigue and chronic infections, a college student who has missed one or more semesters due to illness, or a young mother whose marriage is in distress because of her health, learning strategies for developing resilience can help. Understanding the role of close, supportive relationships, both within the family and beyond, is an important ingredient in living well in each of these situations and in each successive stage of life.

Research, according to the APA, suggests that close relationships are key ingredients in developing resilience. Reaching out to loved ones can be an important part of this process. When marriages are troubled, the support of extended family and professional counseling from providers who understand the ravages of chronic illness can be essential. And, for the college student, close

relationships with peers, student support services and college and university counseling and health resources can be equally essential. It is vitally important to establish good communication with caregivers, healthcare providers and other professionals who are part of your support system. Because so little is known about many immune deficiencies, providing information about your condition to physicians who may not otherwise understand what you are experiencing is advisable. For example, unless physicians are knowledgeable about PIDD, they may not understand that antibiotic therapy may be needed for far longer than normally expected for a particular infection.

Careful planning is another important part of your "resilience tool kit" for managing life with a chronic disorder. Taking its presence into account in educational, career and retirement planning, based on prior health experience, can reduce some of the stress that can occur if goals become unreachable. The ability to make plans and carry them out, often in incremental steps, can aid in maintaining confidence and a positive view of oneself. Success in couple relationships depends on each person's having a deep knowledge and understanding of the other. The chronicity and heritability of disorders such as PIDD therefore require partners to be intimately aware of the disease in general, and the health challenges facing the person with the disease and, therefore, the couple into the future.

It cannot be denied that the stress, uncertainty and losses associated with a chronic disorder may result in painful emotions. Resilience requires facing these emotions and learning strategies for managing them. Having a solid support system can allow for sharing these feelings. Mutually supportive relationships also provide opportunities to give support to others, which can be an ingredient in sustaining a positive view of oneself through difficult times.

Building resilience, like living with illness, is a very personal journey. Strategies that work for one person may not work for another. Variations occur because of gender, ethnic and cultural differences. Some of the strategies recommended by APA are outlined in the sidebar. It is especially important to seek professional help if you experience depression or your ability to function is adversely affected by the emotional impact of chronic illness. A licensed psychologist or other mental health professional can assist you in moving forward and in developing your resilience strategies. ■

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*Dr. Reginald Nettles is a psychologist in private practice in Columbia, Md., and a professional life coach. He has X-linked agammaglobulinemia, a primary immune deficiency. For additional information, contact Dr. Nettles at editor@igliving.com.*

*\* For additional information on the APA Resilience Campaign and other psychological self-help resources, go to <http://www.apahelpcenter.org/> and search site for "road to resilience."*

## 10 Ways to Build Resilience

**Make connections**

**Avoid catastrophizing**

**Accept that change happens**

**Move toward your goals**

**Take decisive actions**

**Seek opportunities for self-discovery**

**Nurture a positive view of yourself**

**Keep things in perspective**

**Maintain a hopeful outlook**

**Take care of yourself!**

# Peripheral Neuropathy, Moving Out of the Shadows

By Angela Macropoulos

**T**he searing pain took 10 days to move from the man's toes across his entire body, creating a sensation that felt "like sunburn rubbed with steel wool."

Another man, whose legs have come to feel thick, heavy and hard to move "like tree trunks," tied the much slower progression of the condition in his body to toxins he inhaled while working as a fire marshal at the World Trade Center on September 11, 2001.

And it's been 15 years since a woman with the same affliction noticed that she would walk out of her shoes because she couldn't feel her feet.

"I'm trying to stay positive even though my neurologist told me to go home and pray," said Carolyn Burgess, 61, of Spartanburg, S.C.

All three have peripheral neuropathy, a term that encompasses a range of disorders that injure the nerves that affect the use of one's limbs. In the United States, the disease affects nearly 20 million people, which is more than are affected by multiple sclerosis worldwide.

Peripheral neuropathy was discovered more than 100 years ago, but until recently it has remained relatively unknown beyond its victims and the doctors who treat them.

"It's been the stealth disorder," said Donald G. Jacob, executive director of The Neuropathy Association in New York.

Johnny Cash, Julia Child, Janet Leigh and Bobby Short all had the disease. Mary Tyler Moore has it, too. Andy Griffith had an acute form, Guillain-Barré syndrome, which can lead to paralysis and respiratory failure.

But no celebrity has stepped forward to put a national spotlight on the disease the way Michael J. Fox has for Parkinson's disease and Montel Williams has for multiple sclerosis. Some engaged in the fight against peripheral

neuropathy believe that has compounded the difficulty in improving diagnosis and treatment.

Doctors first told Cash he had Parkinson's disease. Later, they said he had another rare condition, Shy-Drager syndrome.

"Now they say it's autonomic neuropathy," Cash said when he finally discussed the disease in an interview with Universal Music while promoting his final album in 2003. "I'm not sure what that means, except I think it means that you're getting old and shaky."

Without a proactive celebrity face, change is slow, but it is coming.

The Neuropathy Association lobbied Congress successfully last year to increase funding to the National Institutes of Health (NIH) for research of neurological diseases by \$51 million. Next year, the NIH is expected to spend \$1.5 billion studying such disorders.

The most common forms of the disease are triggered by diabetes, autoimmune reactions, cancers, AIDS, toxins, viruses and nutritional imbalances. "Although diabetes is the most common cause, 20 percent are 'idiopathic,' meaning no specific origin can be found," said Dr. Thomas Brannagan, Cornell University.

Though there are many causes and types of neuropathy, patients usually experience similar symptoms. Sufferers of one common type develop a lack of position sense.

"I cannot close my eyes and maintain my balance," said Irene Beer, 70, of New York. "I need grab bars and a seat in the shower."





Treatments vary, but they generally start with drugs like the anti-seizure medication Neurontin for pain management. Then, doctors often prescribe corticosteroids like prednisone and treatments like blood plasma exchange and intravenous infusion of immune globulin to stall progressive nerve injury.

One challenge for healthcare providers has been to inform the public of symptoms and possible treatments. Groups such as The Neuropathy Association and [braintalk.org](http://braintalk.org) use the Internet to offer patients educational and emotional support, but there are many instances in which the disease has been misdiagnosed as multiple sclerosis, lupus or Lou Gehrig's disease.

"With sensory symptoms, especially those of neural pain, most physicians not familiar with neuropathy—and that's most of them—tend to think of multiple sclerosis first, or maybe spinal compression, and if tests for those don't pan out, they have little idea what might be going on," said Glenn Ribotsky, a patient with the disorder. "It took the skin biopsy three months after the onset to document that I have a small-fiber sensory syndrome."

Neurologists who specialize in the disease are frustrated that health insurance plans increasingly rely on evidence from blinded controlled medical trials before they will cover treatment. With peripheral neuropathy, there aren't enough such trials from which to draw evidence. Dr. Norman Latov, of Cornell University, has diagnosed several patients with demyelinating polyneuropathy, but their insurance would not cover treatment. "'Evidence-based' guidelines is doublespeak because guidelines use evidence selectively," Latov said. "Clinical treatment develops through experimentation and observation. We need to do what we need to, to help patients."

Yet, Latov said, it is an exciting time for research. Last year, the FDA approved Cymbalta for pain from diabetic neuropathy. It is the first drug specifically for the disease. "Hopefully, there will be more work in neuro regeneration," Latov said.

Joe McAuley, 47, the man whose legs felt like tree trunks, found relief for foot pain with a device that electrically stimulates nerves. McAuley also takes vitamin B supplements. He said his feet feel somewhat better, though his condition played a part in his decision to leave the New York City Fire Department in 2003.

Ribotsky, 44, the man with pain that moved from his toes to his entire body, said the pain has dwindled now that he takes megadoses of the drug Neurontin. When it does flare up, he said, his hands, feet, left shoulder and abdominal muscles hurt as though he has had a series of bee stings.

Burgess, whose doctor told her to go home and pray, broke both ankles when she fell due to poor balance. She uses a walker both inside and outside her home. Burgess said she was devastated that she had to give up singing in her Baptist church because she feared falling from the choir loft.

"When you can't do ordinary things for yourself, it takes the stuffing out of you," Burgess said. "I have faith God is going to use this for some good, because it would be easy for me to give up hope and not try."

Because neuropathy is finally moving onto the public's radar screen, perhaps someday soon there will be an articulate, notable advocate who will give Burgess, and all those who suffer from neuropathy, hope for more research and better treatment. ■

# You Are Not Alone!

By Dayna Fladhammer



*Dayna Fladhammer's daughter Kate supports her friend, Arianna Kazemi, who also receives IG treatment.*

Parenting under the best of circumstances is a difficult endeavor. Add to the mix a chronic health condition, and being a parent can seem totally overwhelming. This is also true of parenting a child with primary immune deficiency disease (PIDD), which bears with it a whole unique set of rules, obstacles and fears.

For many families, the time leading up to a diagnosis of their primary immune deficient children is filled with constant illness, isolation and fear for their children's futures. A diagnosis can be both a relief and devastating at the same time.

When my first child was finally diagnosed after two hospitalizations in four months, countless visits to specialists and what seemed like daily visits to the pediatrician, my husband and I were both relieved that we had the answers, yet intimidated by the sheer volume of what we needed to learn in order to help her. But parenting a PIDD child does not have to be overwhelming, and one of the important steps toward gaining control is becoming an active member of the PIDD community.

Kidshealth.org maintains a list of suggestions from clinical social workers for parents dealing with chronic illness (see the full article at [http://www.kidshealth.org/parent/system/ill/seriously\\_ill.html](http://www.kidshealth.org/parent/system/ill/seriously_ill.html)). They recommend, among other things:

1. Consult other parents in support groups at your care center or hospital. They can offer information and understanding.
2. Explore support groups for parents who have children with the same or similar illness.

Connecting with other families can be one of the most affirming steps you'll take on this journey. Other parents may have already faced the issues you're facing, they may have tips for dealing with issues that arise, or you may just feel comforted to be sitting next to someone who is going through the same medical maze as your family.

Recently, as I sat down to dinner at an Immune Deficiency Foundation (IDF) and NuFACTOR-sponsored weekend retreat in Carlsbad, Calif., I looked around and heard the noise level of patients, families, doctors and industry representatives talking and bonding with one

another. I took a moment to burn the image into my memory forever. I felt a particular joy when I turned around and saw three couples, all parents of X-linked agammaglobulinemia (XLA) patients, engaged in deep conversation. I knew from a previous discussion that one of the couples had never before met another parent of an XLA child. I can remember feeling my own sense of hope and community when I finally met another PIDD parent. By the smiles on the parents' faces, I'm fairly sure they felt the same way.

Our first two children were diagnosed immune deficient within six months of each other, and my husband and I felt as though we were the only parents on the planet navigating our way through immune deficiencies. Our first step was to start scouring the internet for information. I found and joined an Internet chat group for pediatric PIDD parents. Having the instant support of 300 parents of PIDD kids was an invaluable tool. The other parents gave us suggestions of questions to ask of our doctors, a crash course in immunology and practical advice as we started immune globulin treatments. They commiserated with us when our infant son was also diagnosed, bringing our total to three immune deficient children.

At the summer 2005 IDF National Conference, parents were able to meet and discuss issues they face and the difficulties of raising a child with an immune deficiency. Finding that other parents experience some of the same issues, have the same concerns and need the same support was so rewarding and comforting for us. Furthermore, the shared experiences led us to alter some of our parenting strategies to avoid repeating other parents' mistakes.

Connecting with other families is not only good for the parents, but can also be a wonderful experience for our children. Last August, I sat with a friend as her PIDD daughter was receiving her first immune globulin infusion.

I was so grateful she was not going through it alone. The night before, my 4-year-old son helped prepare the 7-year-old girl, showing her what to expect with photographs of his own infusion. Even at 4, he wants to be connected to others dealing with the same issues. Our children benefit from meeting others and realizing they are

not alone. Sharing their experiences can give children an excellent sense of accomplishment and control over their disease.

A national survey conducted by the IDF estimates there are 50,000 patients in the United States living with immune deficiencies. You do not have to be alone on this journey.

Support is readily available for those who seek it. ■

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*Dayna Fladhammer is a parent of three children with primary immune deficiency disease. She can be reached at editor@igiving.com.*

## The Path to Support

1. Join an internet chat group for PIDD patients or parents. There are multiple groups—some are general groups for all PIDD patients, some are specialized for specific diseases such as XLA, so check on Yahoo, Google and MSN.
2. Register for the Immune Deficiency Foundation (IDF) mailing list at [www.primaryimmune.org](http://www.primaryimmune.org).
3. Attend every local event that you can, and, if at all possible, plan to attend IDF's National Conference in the summer of 2007.
4. Join the Message Board on the Jeffery Modell Foundation website, at [www.jmfworld.com](http://www.jmfworld.com), and the Forum on the IDF website, at [www.primaryimmune.org](http://www.primaryimmune.org).
5. Ask your child's immunologist, pediatrician and infusion nurse to connect you with other families dealing with PIDD.
6. The IDF has a peer contact program. Ask to be connected with other families in your area.
7. Visit the Baxter website at [www.immunedisease.com](http://www.immunedisease.com), and read the "MyStory" interviews.
8. Talk freely about your child's condition to anyone who will listen. You never know, while you are educating others about PIDD, you may run into another family in a similar situation.

## MANUFACTURER News

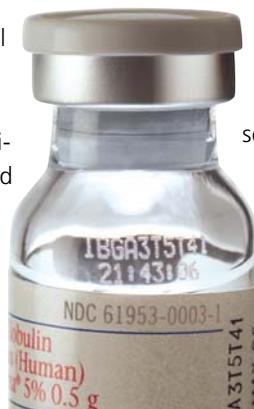
### Grifols Safety Innovation: Laser Etched Vials

by Emily Pulley

**W**ith the growing concerns about adulterated and mislabeled products, Grifols is one manufacturer that has voluntarily introduced changes to its packaging to help deter such an occurrence.

Even though more than 20 million grams of Grifols' IVIG Flebogamma have been used worldwide since licensed in 1992, the company continually strives to produce the safest product possible—whether it's the liquid in the vial or what's on the vial itself. Grifols recently announced that all products available in the United States will be laser inscribed with the lot number.

"Since first licensed in 1992, we have never experienced a product recall for Flebogamma," said Raymond Liu, Grifols' director of marketing. "However, with our commitment to the patients who have come to rely on our products, we are on a constant quest to provide the safest products possible. By implementing the laser etching, we are confident this will aid our exemplary safety record."



The laser etching correlates with the lot number on the vial's label. The lot number correlates with filed data, such as the date of production, expiration of the product and vial size. This helps deter counterfeiters from diluting products and relabeling, which is, unfortunately, a real problem that has occurred with other products. In the case of Flebogamma, Grifols takes additional protective steps by etching a filling sequence number

on the vial that corresponds with a recording of the entire filling sequence. This means that each vial is numbered like a piece of artwork with its own unique identifier number, and, if ever needed, Grifols can see a recording of that exact vial being filled.

Distributors that are concerned with the chain of custody or pedigree of the products they distribute appreciate such safeguards—and informed consumers will, too. ■

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*Note: Since the laser number is etched prior to labeling, the label may, on rare occasions, obscure the number, but the numbers are accessible if needed.*

# On Your Own: Transitioning Teens

By Emily Pulley

Once a week, Keegan McFalls walks to the student health building at Brigham Young University (BYU) to give himself a subcutaneous infusion of immune globulin (SCIG). The immune globulin keeps his

immune system working, allowing his body to fight off infections. Keegan, 18, has Common Variable Immune Disease (CVID), and he doesn't think it's any big deal. During the two-hour infusion he watches a movie, plays pool or attends a class seminar—all without attracting attention.

Keegan and his brother, Konner, 20, were both diagnosed with CVID as children, and their conditions haven't dampened their ambitions: Keegan hopes to attend law school after BYU, while Konner, a student at Evergreen State University in Olympia, Wash., wants to be a college photography professor.

Though their ambitions are well defined, Keegan and Konner have already achieved a lot. Not only have they made the transition from their family home into college life, they've done so while meeting the challenges of managing the disease they have in common.

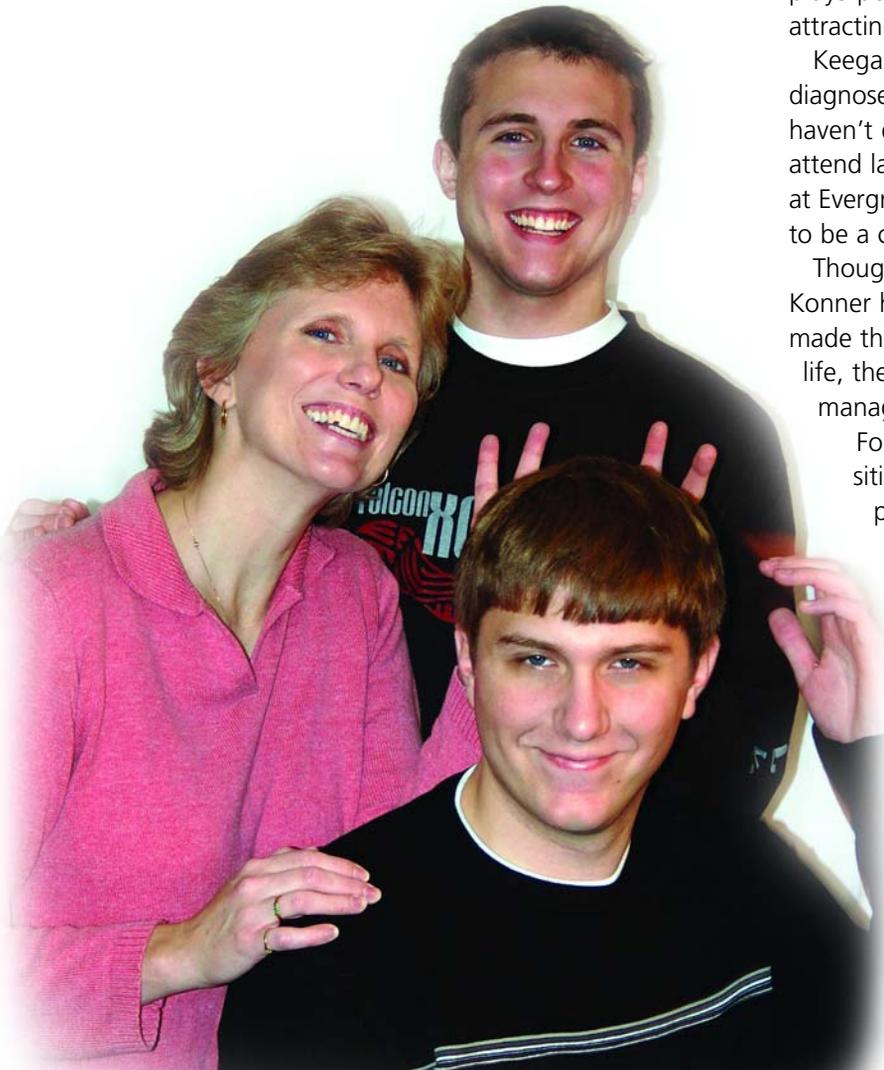
For a young person with a chronic condition, transitioning to adulthood takes years of planning and practice. The McFalls family offers this advice:

Children first must understand their disease state.

At age 13, Konner was fed up with his infusions and asked his mom, Kris McFalls, if he could stop taking them. When summer break came, she let him stop, with the support of his physician. After a couple of months, he wasn't feeling well and resumed his infusions. Kris says she allowed him to stop because she wanted Konner to understand the importance of the infusions and let it be his choice to take them.

Today, Konner uses a port for his infusions and is assisted by his mom, who visits his dorm room and helps him connect the IV.

*Kris, Keegan (standing) and Konner McFalls*



“My transition has been easy,” said Konner. “I knew anywhere I went I was going to be able to get my medicine. It was not too much of a change from my life as it was.”

Kris has many tips for families with transitioning teens. Parents and physicians should share information to help educate young patients. Young people should be encouraged to ask questions during doctor visits. If routine treatments are needed, children should be taught to help themselves or they should know enough to be able to instruct someone to help them.

In fact, Keegan now gives himself infusions and handles his healthcare needs on his own. “My transition was not too difficult,” said Keegan. “The only part I was worried about was whether or not I would do the SubQ [subcutaneous] infusion the right way. After doing the infusion a few times, I got used to it. From there it was easy. The only thing difficult to cope with was figuring out the best way to explain to people why tubes were coming out of my stomach.”

Other issues transitioning teens must consider include getting their own health insurance, knowing the names of their medications and how they are administered, understanding any allergies they have, recognizing the signs of possible side effects of the medications, making their own medical appointments, and learning to eat a healthy diet and exercise regularly.

Kris says her sons always have been independent, making the transition to college a smooth one for both young men. To facilitate his transition, Keegan switched from using a port to the more portable SCIG infusion method, so his weekly infusions take little effort and allow him to stay active during the treatments. Konner is planning to switch to subcutaneous infusions, which will allow him even greater independence.

Planning is the most critical transition tool, according to Kris, who raised her

kids as a single mom. She remembers that Keegan seemed to be constantly ill as a baby. After repeated trips to the doctor, Keegan was finally diagnosed with CVID at age 3. Because this diagnosis came the week of a big camping trip, Kris says her first response to the doctor was, →

## Teens and Parents: Start Your Transition Today!

Here is a helpful list to get you started with your transition plan. Respond to each point with **Yes**, **Sometimes** or **No**—and have your parents do the same. Then, compare answers. For every **Sometimes** or **No**, set a date to turn the **Sometimes** or **No** into a **Yes!** For more in-depth worksheets go to [www.cms-kids.com/CMSNTransition.htm](http://www.cms-kids.com/CMSNTransition.htm).

	YES	SOMETIMES	NO
1. I know my diagnosis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I can explain my symptoms to medical professionals without help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I carry an insurance card.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I carry emergency medical information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I know what medications I take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I know the doses of my medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I know what the medications are for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I know the possible side effects of my medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I know what to do if I experience a bad reaction from medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I know what my allergies are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I have an EpiPen and know how to use it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I call for prescription refills myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I can tell a medical professional about my health history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I have made my own appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I ask questions at my health appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I keep an infusion log.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I know what a 504 plan and an IEP are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I have a plan for life after high school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I know what I need to do for healthcare coverage after I turn 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I know what a co-pay is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I have paid a co-pay myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I have my own checking account with a debit card.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I order my own infusion supplies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I know what doctors and hospitals I can use in an emergency under my insurance policy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I have chosen a primary care doctor to take over my care from my pediatrician.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I know my doctor's phone numbers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I eat healthy foods and get exercise.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

“Can we still go camping?” The answer was yes, and that was the beginning of Kris’ education about living with a chronic disease. Shortly after Keegan’s diagnosis, she suspected her older son had the disease also. Tests confirmed her suspicions. To arm herself, she learned all she could about immune deficiency and eventually volunteered for the nonprofit Immune Deficiency Foundation. Today, Kris works as an IG specialist for NuFACTOR, a specialty pharmacy providing home delivery of healthcare products and services.

Kris says her sons have always been determined to not let CVID or any other health problems stop them from achieving their goals. In seventh grade, Keegan’s asthma was flaring up because of chronic infections. Defying his health problems, he decided to become a runner, and soon he was on the cross-country team. “I came to understand the need for a transition plan because I knew I wanted Konner and Keegan to be as happy and independent as possible,” said Kris. “I knew I wasn’t always going to be there for them. I had to be willing to let them make mistakes and learn while they were still at home. That wasn’t always easy, but it gave me more confidence that once they were on their own, they would do just fine.”

Both Keegan and Konner have high hopes for the future, but they also have some concerns. Keegan wants to run his own business, but wonders if he’ll be able to buy a health insurance policy. And, while it is not proven that immune deficiencies are genetic, it is highly possible they are. Both young men want to be married eventually and have kids one day. Of course, they worry about passing the gene to their children, who could be carriers even if they do not become ill, all of which requires additional thought and planning.

Today, there are many resources for young people with CVID as they plan for transitioning to adulthood, including their physicians, the Internet, national organizations and local support groups. Sometimes just talking with someone who is going through a similar situation can ease the stress and confusion.

For any teen, becoming independent takes planning and forethought, but for a teen with an immune deficiency, it is a more complicated process that should begin as early as possible. By a child’s preteens, a transition schedule should be made so the child can become prepared to independently manage his or her disease by age 18. And, as awareness grows within—and about—the immune deficient community, so do the resources for transitioning teens. ■

## Looking for College Scholarships?

There are many scholarships available for students with conditions considered disabling. Here are just a few:

### **Immune Deficiency Foundation Scholarship**

This one-time award is available to individuals diagnosed with a primary immune deficiency disease.

<http://www.primaryimmune.org/services/scholarship.htm> 800-296-4433

### **The ELA Scholarship**

This scholarship provides financial assistance to women with physical disabilities who are enrolled in a graduate program in a college or university in the United States.

<http://www.ela.org/scholarships/scholarships.html> 626-398-8840

### **Bank of America Abilities Scholarship Program**

These scholarships are awarded to students with disabilities who have a career interest in finance, business or computer systems.

[http://www.scholarshipprograms.org/bada/bada\\_2005\\_ins.htm](http://www.scholarshipprograms.org/bada/bada_2005_ins.htm) 864-268-3363

### **Foundation for Exceptional Children**

The Stanley E. Jackson Award for Gifted/Talented Students is given to students with a disability.

<http://yesican.cec.sped.org/scholarship/index.html> 800-224-6830

### **Joyce Walsh Junior Scholarship for the Handicapped**

This scholarship is awarded to disabled members of the National Federation of Music Clubs.

<http://www.mfmc.net/scholarships.html> 317-638-4003

### **Panasonic Young Soloists Award**

This award is given to vocalists or instrumentalists under age 25 who are permanently disabled and interested in studying music.

[http://www.panasonic.com/corp\\_cont/celebrating.asp](http://www.panasonic.com/corp_cont/celebrating.asp) 202-628-2800

### **Horatio Alger Association Scholarship Program**

The Horatio Alger Association provides financial assistance to students who have exhibited integrity and perseverance in overcoming personal adversity and who aspire to pursue higher education.

<http://www.horatioalger.com> 703-684-9444

### **Central Intelligence Agency: Undergraduate Program**

The CIA Summer Internship Program is open to undergraduate students, particularly minorities and people with disabilities, who have completed one or two years of college-level academic study.

<http://www.cia.gov/employment/student.html> 800-368-3886



**GBS/CIDP** Foundation International  
Serving patients of GBS, CIDP and Variants with support, education and research

Guillain-Barré Syndrome • Chronic Inflammatory Demyelinating Polyneuropathy



## An Overview of Guillain-Barré Syndrome

### What Is Guillain-Barré Syndrome?

Guillain-Barré (Ghee-yah Bah-ray) syndrome (GBS), also called acute idiopathic polyneuritis and Landry's ascending paralysis, is an inflammatory disorder of the peripheral nerves, those outside the brain and spinal cord. It is characterized by the rapid onset of weakness and often paralysis of the legs, arms, breathing muscles and face. Abnormal sensations often accompany the weakness.

Many patients require intensive care during the early course of their illness, especially if support of breathing with a machine is required. Although most people recover, this can take months, and some may have long-term disabilities of varying degrees. Less than 5 percent die. GBS can develop in any person at any age, regardless of gender or ethnic background.

### How Is GBS Diagnosed?

Quite often, the patient's symptoms and physical exam are sufficient to indicate the diagnosis. The rapid onset of (ascending) weakness, frequently accompanied by abnormal sensations that affect both sides of the body similarly, is common. Loss of reflexes, such as the knee jerk, is usually found. To confirm the diagnosis, a lumbar puncture to find elevated fluid protein and electrical tests of nerve and muscle function may be performed.

### How Is GBS Treated?

Because progression of the disease in its early stages is unpredictable, most newly diagnosed patients are hospitalized and usually placed in an intensive care unit to monitor breathing and other body functions.

Care involves use of general supportive measures for the paralyzed patient and also methods specifically designed to speed recovery, especially for those patients with major problems, such as inability to walk.

Plasma exchange (a blood "cleansing" procedure) and high doses of intravenous immune globulin are often helpful to shorten the course of GBS.

Most patients, after their early hospital stay and when medically stable, are candidates for a rehabilitation program to help regain muscle strength as nerve supply returns.

### What Causes GBS?

The cause of GBS is not known. Perhaps 50 percent of cases occur shortly after a viral or bacterial infection such as a sore throat or diarrhea. Many cases developed in people who received the 1976 swine flu vaccine. Current theories suggest an autoimmune mechanism in which the patient's defense system of antibodies and white blood cells are triggered to damage the nerve covering or insulation, leading to weakness and abnormal sensations.

### Need Help?

If you have GBS or know someone who does and would like assistance or information, contact the Guillain-Barré Syndrome Foundation International. If you would like to form a local support group chapter or learn of local physicians who are familiar with GBS, contact us. If you are a healthcare professional and would like literature or emotional support for your patients, feel free to contact us. We are here to serve you. ■



610-667-0131 ■ Fax 610-667-7036  
www.gbsfi.com ■ info@gbsfi.com

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# Immune Globulin Therapy: a Brief Introduction

By Shirley German Vulpe, EdD

Immune globulin (IG) therapy is a real lifesaver! This article answers some frequently asked questions about this important therapy: It defines what IG is, how IG is prepared, IG brand names, methods of administering IG, and currently effective therapeutic uses of IG.

## What Is Immune Globulin?

Immune globulin is a purified component of the blood. It is used in a number of disorders, including immune deficiency diseases, such as hypogammaglobulinemia, and a multitude of autoimmune disorders, such as primary immune deficiency diseases, peripheral neuropathies, Guillain-Barré syndrome, myositis, multiple sclerosis, etc.

Immune globulin is also known as gamma, gamma-globulin, immune globulin intravenous, IVIG, IgG and IGIV. Whatever name you give it, immune globulin is a sterile solution of highly purified proteins extracted from large pools of human plasma, the liquid portion of blood, collected from 50,000 to 60,000 people. All donors are screened according to American Red Cross standards, and their blood is tested for evidence of any transmissible or infectious diseases. Any blood suspected of having a problem, such as HIV or hepatitis, is discarded.

Immune globulin naturally occurs in the human body. It is made of protein molecules, also called antibodies, produced by B cells when they respond to a foreign substance in the body. Antibodies are a part of our body's multifaceted, amazingly coordinated immune system. Antibodies defend us, in coordination with other immune system cells (T-cells, phagocytes and complements), against a broad spectrum of bacteria, fungi, parasites and viruses. The five types of immune globulins—IgG, IgA, IgM, IgE and IgD—each defend us against these "invaders" differently.

## How Is IG Derived?

Therapeutic immune globulin is produced from plasma recovered from whole human blood. First, all red and white cells and platelets are removed from the blood.

Then the remaining liquid plasma is chemically treated to precipitate purified immune globulins (antibodies). The majority of the immune globulin produced is of the IgG class. Many fractionation and filtering processes are used to separate out all other blood proteins and kill any viruses or germs that may remain in the plasma.

The U.S. Food and Drug Administration (FDA) is the federal organization that approves the use of therapeutic agents such as IG. FDA approval is given for use of a product for specific diseases, under certain conditions and via certain methods of administration. The approval process is strenuous, requiring well-controlled patient studies documenting that the product is safe and effective.

Currently, IG is FDA-approved for intramuscular or intravenous delivery. A physician must prescribe and monitor its use, because FDA-approved doses are different for each patient, based on body weight and the condition for which they are being treated. Some physicians have determined that not all patients tolerate intravenous IG delivery well. In these cases, they recommend subcutaneous administration (SCIG), for which the FDA recently approved a product.

## What IG Products Are Available?

IG is available in several brand names, made by various pharmaceutical companies. The following IG products are FDA-approved for use in the United States:

<u>Product</u>	<u>Manufacturer</u>
Carimune NF	ZLB Behring
Flebogamma	Grifols
Gammagard 5% S/D	Baxter
Gammagard 10% S/D	Baxter
Gammagard Liquid	Baxter
Gammar-P IV	ZLB Behring
Gamunex	Talecris
Octagam	Octapharma
Polygam S/D	Baxter
Vivaglobin	ZLB Behring

## When Is IG used?

IG is used in the treatment of primary immune deficiencies and autoimmune diseases that disrupt the delicate balance of the operation of the human immune system. IG is also used to treat a variety of infections—bacterial and viral.

The members of the primary immunodeficiency committee of the American Academy of Allergy, Asthma and Immunology, in their paper on the appropriate use of IG,<sup>1</sup> list the uses of IG for disease states classified into various categories, including **Definitely Useful**, **Probably Useful** and **May Provide Benefit**. Their classifications are based on currently available evidence. As additional evidence becomes available, benefit categories may change. Those classifications for which benefits have been proven are listed at right.

## Definitely Useful

- Primary immunodeficiency
- Idiopathic thrombocytopenic purpura
- Graves' ophthalmopathy
- Demyelinating polyneuropathies
- Kawasaki disease

## Probably Useful

- Chronic lymphocytic leukemia with reduced IgG and history of infections
- Prevention of bacterial infection in HIV-infected children
- Dermatomyositis and polymyositis
- Myasthenia gravis and Eaton-Lambert myasthenia syndrome
- Established bacterial sepsis
- Toxic epidermal necrolysis and Stevens-Johnson syndrome

## May Provide Benefit

- Prevention of neonatal sepsis
- Post transfusion purpura
- Autoimmune cytopenias
- Systemic lupus
- Severe rheumatoid arthritis
- Antiphospholipid antibody syndrome in pregnancy
- Antineutrophil cytoplasmic antibody syndromes
- Severe persistent high dose steroid-dependent asthma
- Multiple sclerosis (relapsing-remitting)
- Intractable childhood epilepsy
- Prevention of infection and acute graft versus host disease post-hematopoietic stem cell transplantation
- Prevention of acute humoral rejection in renal transplantation
- Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS)

Immune globulin is indeed a lifesaver! For more information about this amazing therapeutic, visit the following websites:

[www.medlineplus.gov](http://www.medlineplus.gov)

[www.immune-globulin.com](http://www.immune-globulin.com)

[www.baxter.com](http://www.baxter.com)

[www.grifolsusa.com](http://www.grifolsusa.com)

[www.octapharma.com](http://www.octapharma.com)

[www.talecris.com](http://www.talecris.com)

[www.zlbbehring.com](http://www.zlbbehring.com) ■

<sup>1</sup>Orange, J.S., MD (editor) Practice paper on the appropriate use of intravenously administered immunoglobulin (IGIV), generated by the primary immunodeficiency committee of American Academy of Allergy, Asthma and Immunology, Aug 2005, [http://www.aaaai.org/media/resources/academy\\_statements/practice\\_papers/igiv.pdf](http://www.aaaai.org/media/resources/academy_statements/practice_papers/igiv.pdf).

# How Safe Is the U.S. Pharmaceutical Supply Channel?

*And Why You Should Care!*

By Kit-Bacon Gressitt

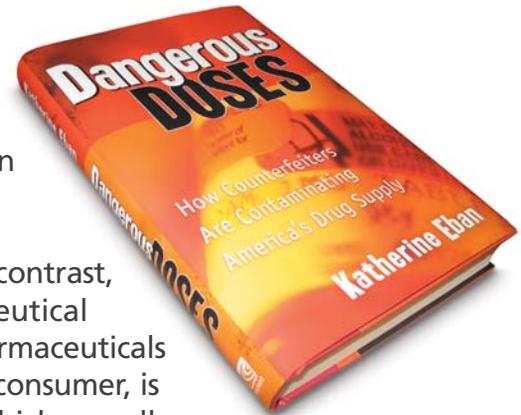
In 2002, investigative reporter Katherine Eban received a tip from a government source, urging her to look into how counterfeit drugs were making their way into U.S. pharmacies.

In May 2005, Harcourt published Eban's book, "Dangerous Doses: How Counterfeiters Are Contaminating America's Drug Supply."

On November 1, 2005, the House Committee on Government Reform's Subcommittee on Criminal Justice, Drug Policy and Human Resources held a hearing on "Sick Crime: Counterfeit Drugs in the United States," at which Eban testified.

From reporter to author to expert witness is an unusual path. In contrast, what Eban ultimately learned from that first tip is that pharmaceutical counterfeiting is *not* unusual. The supply channel our nation's pharmaceuticals follow, from the manufacturer to the pharmacy to the healthcare consumer, is often convoluted and rampant with vulnerabilities, any one of which can allow counterfeit drugs to enter the supply chain—and end up in your medicine cabinet.

Eban spoke with IG Living about "Dangerous Doses," its genesis and the growing response to it.



**Q:** Who is the most important audience for "Dangerous Doses"?

**Eban:** Anyone who takes medicine. What "Dangerous Doses" and my reporting reveal is that Americans who have gone to their pharmacies and paid top dollar for their medicine have been getting adulterated, recycled, stolen and even counterfeit medicine.

**Q:** How did you discover the counterfeit drug problem?

**Eban:** I'd been an investigative medical reporter for nine years, and I got a tip from a longtime government source who said I should investigate why counterfeits were landing on pharmacy shelves. His statement really surprised me. When most people think of counterfeits, they think of the Internet or Mexico, but this was a situation in which actual counterfeits were reaching our nation's supply, which is assumed to be secure, closed and inviolable.

I did one story on counterfeiting for *Self* magazine. At the time, I wasn't thinking it was an enormous story, but as I began my reporting [on the situation in Florida], I could see just how huge it was. There were layers of complicity. Major wholesalers seeking discounts buy in the secondary market from small, rogue wholesalers. The investigators who were trying to solve the problem

were encountering terrible bureaucracy and apathy. You had situations where Florida bureaucrats were giving licenses to convicted narcotics traffickers, who then became pharmaceutical wholesalers.

Once we realized the magnitude of the story, we went to "60 Minutes." They took our reporting and did a segment on it. I realized pretty quickly that there could be an extraordinary book here, in part because of not only the magnitude of the corruption, but because of this group of investigators in Florida, who called themselves the Horsemen of the Apocalypse. Their struggle was like a movie in the making.

**Q:** Why do you think it is so easy for criminals and careless distributors to participate in the pharmaceutical supply channel?

**Eban:** Consumers just don't know. They have no idea. Most patients who have gotten caught in the crossfire, who have gotten counterfeit medicine, didn't even know that there is a supply chain. They didn't know that their medicine was in the hands of middlemen, between the manufacturer and the pharmacy.

The end result is that they are getting substandard medicine, medicine that may have lost its potency because it was in the trunk of someone's car in hot temperatures,

it was mishandled, and a lot of this medicine is very expensive. It's for patients who need it the most. So, if their medicine is subpotent and it doesn't work, they don't know why it hasn't worked. Most assume it's because they're pretty sick. They don't stop to consider the efficacy of the medicine.

**Q:** What can consumers do?

**Eban:** In order to ask informed questions, consumers need to understand how the supply chain works. They need to understand what the risks are that their medicine faces. Try to determine if your pharmacy has an agreement to buy from a wholesaler that pledges that they purchase all their medicine directly from the manufacturer. Disclosures of the medicine's origin to patients are inadequate. I support the drug pedigree's being passed on to the patient, because if you said to a mom, "You can either get a medicine that's guaranteed safe for your child or you can get a discount on medicine that may have been handled by a narcotics trafficker or moved in the back of a car," who would buy that for their kid? Nobody.

**Q:** What needs to be done to secure the channel?

**Eban:** I think that drugs should make only one stop between the manufacturer and the pharmacy, and that stop should be documented with a pedigree. Everyone who had their hands on our medicine should be regulated, subject to inspection.

Part of the solution is old-fashioned: stronger laws and more enforcement, so that someone who counterfeits

medicine could be prosecuted for attempted murder instead of for misbranding a commercial product and then spend 18 months in jail and pay a nominal fine. The current laws don't clearly outline criminal penalties for adulteration, which is mishandling, exposing the medicine to risk, as a distinct category of misconduct.

**Q:** Has the government responded effectively?

**Eban:** No. We don't have any information as to the size of the problem. The FDA has made guesses, but done no studies. It has capitulated to wholesalers who don't want to reveal where they buy their medicine. With the absence of clear federal guidance, each state has gone off and made their own laws, most of them, until recently, fairly weak.

There needs to be a national solution. The pharmaceutical supply is only as clean as its dirtiest link. So long as there are places in any state where bad medicine can enter the supply chain, then every consumer in the country is at risk. We need uniform standards nationwide.

**Q:** This issue has led you along an interesting path. Where do you go next?

**Eban:** A team of movie producers is exploring the possibility of "**Dangerous Doses**" the movie. If all goes well, we may see it in the theaters. ■

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*"Dangerous Doses" is published by Harcourt Books and can be ordered through [www.dangerousdoses.com](http://www.dangerousdoses.com).*

## What you can do about counterfeit drugs

### Watch what you take

- Be familiar with your medicine. Examine its shape, color, and size.
- If your medicine is in pill, capsule or tablet form, put it in the palm of your hand and examine it under a light before taking it.
- Look for altered or unsealed packaging, or changes in design.
- Make sure the packaging is pristine and has no sticky residue, which can indicate the drug was previously dispensed.

### Observe your symptoms

- Be aware of new or unusual side effects.
- Be concerned if your medicine stops being effective.
- Be suspicious if an injectable drug stings or causes a rash.

### Look for the latest warnings and announcements

- Visit MedWatch at <http://www.fda.gov/medwatch/>, the FDA's website that lists information on drug safety, label changes and voluntary recall announcements.
- Visit your drug manufacturer's website for information on current recalls.

### If you think your medicine is counterfeit

- Tell your pharmacist, your doctor and the manufacturer. Most manufacturers have phone numbers or email addresses for patients with questions and concerns.
- You or your doctor should submit a report to the FDA on the MedWatch site. The form can be found at <http://www.fda.gov/medwatch/report/consumer/consumer.htm>.
- Keep a sample of your medicine as evidence, even if the manufacturer asks you to send it all back.

### Other advice

- Buy only from a reputable and licensed seller. You can check credentials through your state pharmacy board or the National Association of Boards of Pharmacy at [www.nabp.net](http://www.nabp.net).
- If you are buying online, look for approved Internet pharmacies posted at <http://www.nabp.net/vipps/consumer/listall.asp>.
- For more information and articles on counterfeit medicine, visit: Partnership for Safe Medicines: [www.safemedicines.org/who/](http://www.safemedicines.org/who/) National Consumers League: <http://fraud.org/fakedrugs/>.

*Reprinted from "Dangerous Doses" Copyright 2005 by Katherine Eban*

# Ironman Challenger Triumphs Over Neuropathy

From The Neuropathy Association

In the rough and tumble world of women's soccer, goalie Emily Oleksiuk, 24, often overcame pain to become an internationally-ranked player. So, when a rare neuropathy brought pain unlike any she had known, Emily responded by fighting fire with fire. On November 5, 2005, this former soccer star took on and completed the Ford Ironman Florida. The race required athletes to swim 2.4 miles, cycle 112 miles and run 26.2 miles, all in less than 17 hours. Emily's goal was to finish in 15 hours: She clocked in at 15:02.

Emily's illness, Parsonage-Turner syndrome or brachial plexus neuritis, attacks the nerves controlling shoulder and arm muscles. Emily wanted to use the Ironman not only to challenge her illness, but also to increase neuropathy awareness and raise research funds for The Neuropathy Association. As a new patient in search of answers, Emily was committed to supporting the Association's mission to provide patient support and education, facilitate information exchange, advocate for patients and, most important, encourage research into the causes and cure of neuropathies.

"A personal commitment to defeat neuropathy, coupled with competitiveness and athletic ability, will be wings on her feet in the Ironman competition," said Ronnie Chalif, president of The Neuropathy Association.

Emily's iron will was already evident when she stepped onto Penn State's soccer field, where she became a Division I All-American and set Penn State's career records

for shutouts, wins, winning percentage and goals against average. Scouts for the newly formed Women's United Soccer Association (WUSA) took notice of her talent,

and she was drafted into the league as a Carolina Courage team member. However, after playing for only one season—and just one month after the onset of her illness—the WUSA suspended operations.

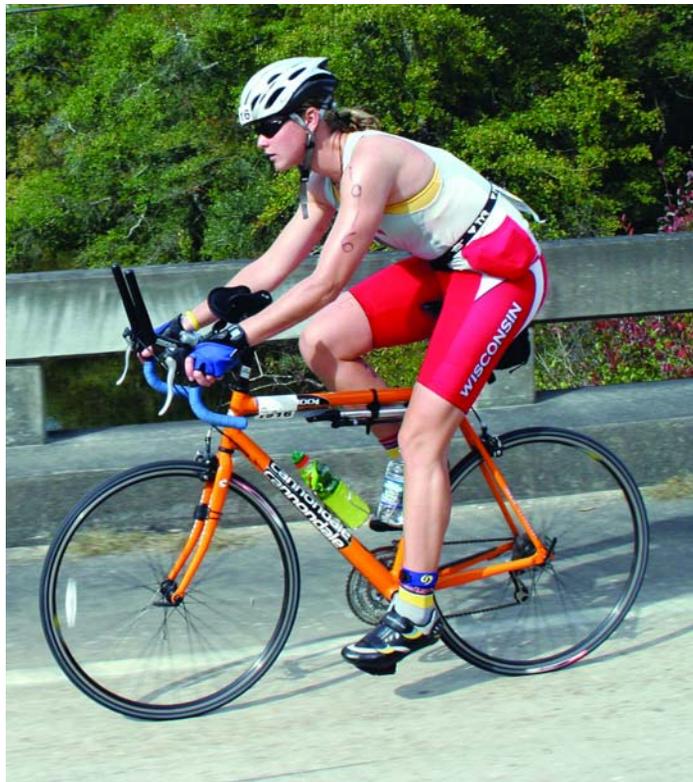
August 18, 2003, brought Emily "the longest and most painful" night of her life.

"The pain was unlike anything I have ever experienced, a deep pain felt all the way to the bone," she recalled. Having spent years monitoring her body to strengthen and enhance her skills for competition, "suddenly, I had to experience pain of unknown origin, and watch my muscles waste away without knowing whether or not I would recover."

EMG (electromyogram) and

nerve conduction analysis resulted in the Parsonage-Turner syndrome diagnosis. She has since been treated with injections of intravenous immune globulin—"healing drop by drop"—and has gradually recovered arm motion and strength.

Emily's expectations for the Ironman were that the rewards would outweigh what she had endured with her illness's onset. She came away with this observation: "When the body demands to stop, and the mind refuses to give in, there is a certain realization achieved that boundaries are meaningless—if you refuse to stop fighting." ■



Emily Oleksiuk conquering the 112-mile bike race.

To learn more about The Neuropathy Association or to make a donation, please visit [www.neuropathy.org](http://www.neuropathy.org).

# Everything You Ever Wanted to Know About...

## ...Guillain-Barré Syndrome (GBS)

### Websites and Chat Rooms

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

### Online Pamphlets

1. A GBS Fact Sheet is found on the National Institute of Neurological Disorders and Stroke website: [www.ninds.nih.gov/disorders/gbs/detail\\_gbs.htm](http://www.ninds.nih.gov/disorders/gbs/detail_gbs.htm).
2. The Mayo Clinic has an overview of Guillain-Barré syndrome at [www.mayoclinic.com/health/guillain-barre-syndrome/DS00413](http://www.mayoclinic.com/health/guillain-barre-syndrome/DS00413).

## ...Myositis

### Websites

1. The mission of The Myositis Association of America, [www.myositis.org](http://www.myositis.org), is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. 202-887-0088
2. Ann, a 35-year survivor of myositis, created this website, full of resources and information on inflammatory myositis diseases: [www.myositisnw.org](http://www.myositisnw.org).
3. When James R. Kilpatrick was diagnosed with inclusion body myositis, there was little knowledge about his disorder. So, he gathered all the myositis information he could and created a website, [www.myositisupportgroup.org/](http://www.myositisupportgroup.org/).

## ...Peripheral Neuropathy (PN)

### Websites

1. 



**THE NEUROPATHY ASSOCIATION®**

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

### Support Groups

Click on the Member Services tab of the website, [www.neuropathy.org](http://www.neuropathy.org), for listings of support groups across the nation.

## ...Primary Immune Deficiency Disease (PID)

### Websites and Chat Rooms

1. 



**IMMUNE DEFICIENCY FOUNDATION**

The Immune Deficiency Foundation (IDF), [www.primaryimmune.org](http://www.primaryimmune.org), is dedicated to improving the diagnosis and treatment of PID through research and education. 800-296-4433
2. The Jeffrey Modell Foundation, [www.jmfworld.com](http://www.jmfworld.com), is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for PID. 212-819-0200
3. 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 "primary immunodeficiency."
4. The American Academy of Allergy, Asthma & Immunology, [www.aaaai.org](http://www.aaaai.org), has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.
5. Baxter's website, [www.immunedisease.com](http://www.immunedisease.com), offers in-depth information on immunology, PID and treatment with intravenous immune globulin. Click on "European" to see SCIG information.
6. The Michigan Immunodeficiency Foundation, [www.midf.org](http://www.midf.org), seeks to improve the quality of life for Michigan residents affected by PID.
7. The International Patient Organization for Primary Immunodeficiencies (IPOPI), [www.ipopi.org](http://www.ipopi.org), promotes the worldwide improvement in the care and treatment of PID patients.
8. To connect to a PID message board, go to [www.jmfworld.com](http://www.jmfworld.com).
9. To chat with peers on IDF's Forum, go to [www.primaryimmune.org](http://www.primaryimmune.org).

### Online Pamphlets

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

## ...General Web Resources

1. For suggestions on how to deal with the medical and emotional impact of caring for an ill child, go to [www.kidshealth.org/parent/system/ill/seriously\\_ill.html](http://www.kidshealth.org/parent/system/ill/seriously_ill.html). →

## Everything You Ever Wanted to Know continued...

2. The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at [www.ncqa.org](http://www.ncqa.org).
3. The nonprofit Patient Advocate Foundation, [www.patientadvocate.org](http://www.patientadvocate.org), seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274
4.  The nonprofit Patient Services Incorporated, [www.uneedpsi.org](http://www.uneedpsi.org), specializes in health insurance premium, pharmacy co-payment and co-payment waiver assistance for people with chronic illnesses. 800-366-7741
5. WebMD, [www.webmd.com](http://www.webmd.com), is a handy medical reference that helps consumers take an active role in managing their health by providing objective healthcare and lifestyle information.

### Books and Articles

1. "21st Century Complete Medical Guide to Primary Immune Deficiency, Severe Combined Immunodeficiency (SCID), Chronic Granulomatous Disease (CGD), for Patients and Physicians," by PM Medical Health News, contains federal government clinical data and practical information for patients and physicians.
2. "A Handbook for Care Givers," by Helen Rummelsburg, gives an account of caring for her husband and offers helpful hints for patients and caregivers. Available at the GBS website bookstore at [www.gbsfi.com](http://www.gbsfi.com).
3. "Anatomy of an Illness," by Norman Cousins, is a bestseller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body's capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
4. "Bed Number Ten," by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
5. "Caring for a Child With GBS," by Patricia Schardt, is a short guide written by a mother of a child with CIDP. Available at the GBS website bookstore at [www.gbsfi.com](http://www.gbsfi.com).
6. "The Confused Consumer's Guide to Choosing a Health Care Plan: Everything You Need to Know," by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.
7. "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.
8. "If You're Having a Crummy Day, Brush Off the Crumbs!," by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.
9. "Inclusion-Body Myositis and Myopathies," by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.
10. "Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration," by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.
11. "Managing Pain Before It Manages You," by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.
12. "Medifocus Guide to Peripheral Neuropathy" is a guide to current and relevant PN research, organized into categories for easy reading.
13. "Myositis—A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References," by ICON Health Publications, is a three-in-one reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.
14. "No Laughing Matter," by Joseph Heller (the best-selling author of "Catch-22"), who teamed up with Speed Vogel, his best friend, to describe Heller's battle with and triumph over GBS.
15. "Not Dead Yet: a Long Strange Trip From Doctor to Patient and Back Again," by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.
16. "Numb Toes and Aching Soles," by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
17. "Numb Toes and Other Woes," by John Senneff, is the second in a series of three books. It focuses on clinical findings and treatment strategies for PN.
18. "Nutrients for Neuropathy," by John Senneff, the third in the Numb Toes series, is focused exclusively on nutrient supplementation as a means for managing PN.
19. "The Official Patient's Sourcebook on Inclusion Body Myositis," by James N. Parker (Editor) and Philip M. Parker (Editor), is a reference manual for self-directed patient research.
20. "Pride and the Daily Marathon," by Jonathan Cole, describes how Ian Waterman was suddenly struck down at work by a rare neurological illness that deprived him of all sensation below the neck, and how he reclaimed a life of full mobility.
21. "Pronoia Is the Antidote for Paranoia," by Rob Breznsy, explores the best way to attract the blessings that the world is conspiring to give us.

### IG Manufacturers Websites

Baxter: [www.baxter.com](http://www.baxter.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)

ZLB Behring: [www.zlbbehring.com](http://www.zlbbehring.com)

### Pump and Needle Websites

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

Repro Med Systems, Inc: [www.repro-med.com](http://www.repro-med.com)

Graseby Marcal Medical: [www.marcalmedical.com](http://www.marcalmedical.com)

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

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*Have something to add to these pages? Please send your suggestions for additions to the IG Living Resources pages to [editor@igliving.com](mailto:editor@igliving.com). In this case, more is indeed better!*

# Travel Tips

By Carol K. Miletti



I travel quite a bit and I've quickly learned some tricks, and my PIDD peers have shared some of their travel tips, too. I hope our ideas will help make your travels safer and more enjoyable.

## The first thing to do is *plan*.

Call your doctor to discuss your proposed itinerary, and assess your risks and your health status *together*. What will you need? Will your doctor be available "just in case"? I created a pretty extensive "just-in-case" bag of tricks after getting sick on vacation in Arizona last year and ending up in urgent care.

### My "just-in-case" bag includes:

- List of all meds
- List of allergies
- Medical info including test results
- Health insurance info
- Antibiotics or a prescription
- Locations of providers and hospitals in area of destination
- Contact info for my doctor and family members
- A backup plan!

I always travel with all of my SCIG meds in a small lunch pack that holds the vials, ice packs, prescription, infusion log and supplies. I've learned to pack extras—if something can break, it will. If you are on immune globulin treatment, you may want to schedule one within 48 hours of leaving and returning.

To mask or not to mask? If you choose to, there are many types of masks available that can protect us from harmful airborne contaminants. Google "face mask" and take your pick.

Remember water, water everywhere. Make sure it's in bottles—and have plenty of it on hand. Speaking of hands, wash them often, using alcohol-based wipes or hand sanitizers.

In case of emergency? I wear a medic alert bracelet and keep a medical card in my wallet. I also inserted the letters ICE (in case of emergency) in front of the names of my emergency contacts in my cell phone.

Don't let the airport wear you out before your trip even begins. If you are fatigued, you won't have much fun. Ask for a wheelchair or a ride to your gate. And speaking of fatigue—sleep, sleep, sleep!—before, during and after your trip. I don't need to remind you of what happens when you get overtired.

Now for some hotel tips. *Always* ask for a nonsmoking room with a refrigerator for storing your meds. Be sure to mention your medical needs, and the hotel cannot refuse you. Do not accept anything less than what you've requested.

If you have mobility issues, ask for a first-floor room or one by the elevators.

Did I forget the most important tip? Have fun! 🍷

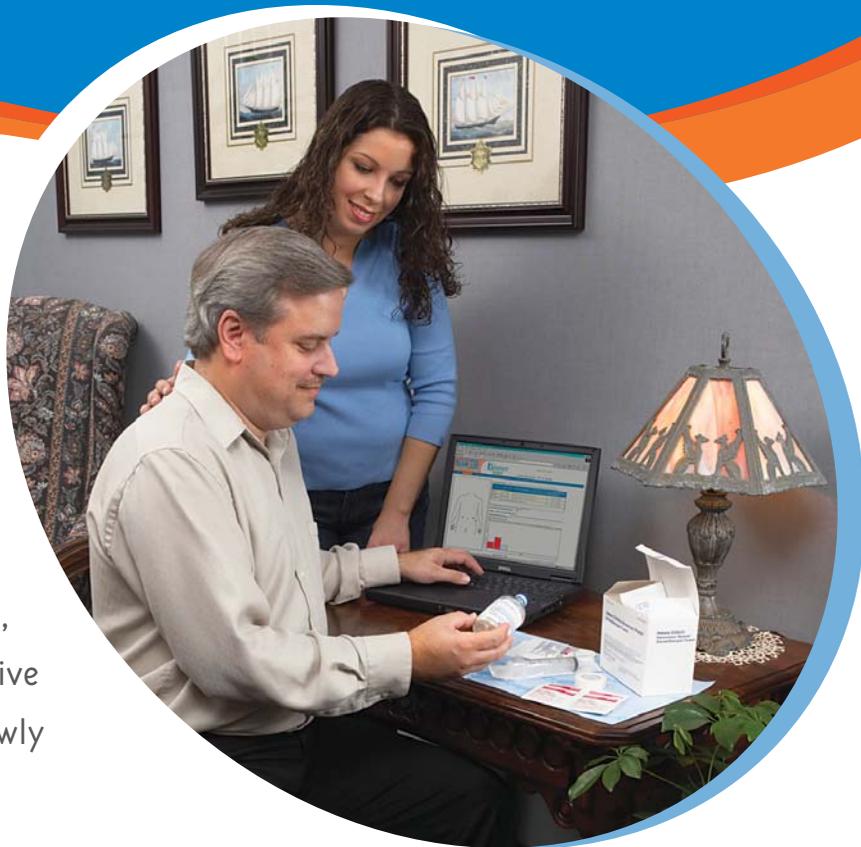
# We know your world

NuFACTOR specializes in supporting your immune globulin therapy in the comfort of your home or office.

We are members of your community, so we know how tough it can be to live with your condition, and, for the newly diagnosed, how scary.

We know how to make your world work a little smoother

Call NuFACTOR at **800-323-6832**  
and ask about our IG Treatment Tracker



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[www.nufactor.com](http://www.nufactor.com)

NuFACTOR's parent company, FFF Enterprises, is the nation's largest distributor of immune globulin. Together, we are dedicated to serving you with caring and integrity.