

# I.G. LIVING!

IMMUNE GLOBULIN COMMUNITY

www.igliving.com

June-July 2007

**Optimizing Nutrition  
for Older Adults**

**Quest for the  
Elusive Diagnosis**

**Cracking the PIDD  
Diagnosis Code**

## Where Does My Immune Globulin Come From?

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

Newsstand Price  
\$2.00

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

A community service from FFF Enterprises and NuFACTOR Specialty Pharmacy Services

#### Advisory Board

Erika Lawrence, PhD

Assistant Professor, Department of Psychology  
University of Iowa

Fred Modell

Co-founder of the  
Jeffrey Modell Foundation

Patricia A. Morrison, RPh

NuFACTOR Specialty Pharmacy Services

Marc Riedl, MD, MS

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

#### Publisher

Patrick M. Schmidt

#### Editor

Kit-Bacon Gressitt

#### Assistant Editor

Cheryl Brooks

#### Contributing Editor

Dayna Fladhammer

#### Copyeditor and Proofing

Jackie Logue

Zachary Pugh

#### Creative Director

Allan Bean

#### Circulation Director

Carrie Craig

#### Advertising Manager

Barry Pawelek

#### Graphic Artists

Allan Bean

Caroline Carlson

Kim Kinman

#### Contributing Writers

Dan Bennett

Ever Fecske

Dayna Fladhammer

Joan Fleitas, EdD, RN

Lauren Gerstmann, MPH

Kit-Bacon Gressitt

Cheryl Haggard

Mark T. Haggard

Kris McFalls

Carol K. Milette

Alma Morales

Megan Reath

Jennifer Richlin, RN, MSN, PNP

Jessica Schulman, PhD, MPH, RD

Jeff Siegel

Michelle Vogel

Shirley German Vulpe, EdD

©2007 FFF Enterprises Inc. All rights reserved.

Please direct editorial, advertising  
and marketing communications to  
41093 County Center Drive  
Temecula, CA 92591

Ph: 800-843-7477 Fax: 951-699-9655

Email: editor@igliving.com  
www.igliving.com

## In this issue...

### Features

8 Cracking the PIDD Diagnosis Code  
By Dan Bennett

10 Optimizing Nutrition for Older Adults  
By Jessica Schulman, PhD, MPH, RD

27 Quest for the Elusive Diagnosis  
By Lauren Gerstmann, MPH

### Departments

IGL Editorial  
3 Who Loves You When You're  
Down and Out?  
By Kit-Bacon Gressitt

Community News  
16 IG Reimbursement Q&A  
By Michelle Vogel and Kit-Bacon Gressitt

Medical News  
20 Where Does My Immune Globulin  
Come From?  
By Kit-Bacon Gressitt

22 Wisconsin Takes the Lead in  
Testing Early SCID Diagnosis  
By Jeff Siegel

26 Immune Globulin Studies Focus  
on Reducing Side Effects  
By Alma Morales

33 MRSA: What Is It and  
How Can It Be Prevented?  
Jennifer Richlin, RN, MSN, PNP

Parenting  
42 You Know You Parent a  
Chronically Ill Child When...  
By Dayna Fladhammer

Lifestyle  
4 Band-Aides & Blackboards  
By Joan Fleitas, EdD, RN

6 Searching for Miller Fisher  
By Jessica Schulman, PhD, MPH, RD

14 Lessons From Kris, J.J. and Shaggy  
at Northwest Folklife  
By Mark T. Haggard

18 Homskool Mi PIDD Kidz?  
By Cheryl Haggard

36 The Freedom to Keep Moving  
By Megan Reath

37 Ask Kris

40 Everyone Has a Story,  
and This Is Kate's  
By Carol K. Milette

41 Ha, Ha, Ha, Ha, Ha!  
By Ever Fecske

43 Let's Talk!  
By Shirley German Vulpe, EdD

44 IG Living Resources

Correction: In the April-May 2007 article, "Myasthenia Gravis and IVIG Therapy," Hayward Auerbach's name was misspelled. We regret any confusion our error may have caused.

### 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.

IG Living, published bimonthly, is a community service provided by FFF Enterprises and NuFACTOR, 41093 County Center Drive, Temecula, CA 92591, 800-843-7477 x1143, fax 951-699-9655.

Subscriptions to IG Living are free, and readers may subscribe at [www.igliving.com](http://www.igliving.com) or by calling 800-843-7477 x1143.

The opinions expressed in IG Living are those of the authors alone and do not represent the opinions, policies or positions of FFF Enterprises, NuFACTOR, the Board of Directors, the IG Living Advisory Board or editorial staff. This material is provided for general information only. FFF Enterprises and NuFACTOR do not give medical advice or engage in the practice of medicine. FFF Enterprises and NuFACTOR under no circumstances recommend any particular treatment for any individual and in all cases recommend that individuals consult with a physician before pursuing any course of treatment.

All manuscripts should be submitted in MS Word, in Arial font. Manuscripts should be between 650 and 1,300 words in length, with unjustified margins and without any other formatting. Email manuscripts to [editor@igliving.com](mailto:editor@igliving.com). IG Living retains the right to edit submissions. The contents of each submission and their accuracy are the responsibility of the author(s) and must be original work that has not been, nor will be, published elsewhere, without the written permission of IG Living. A copyright agreement attesting to this and transferring copyright to FFF Enterprises will be required. Acceptance of advertising for products and services in IG Living in no way constitutes endorsement by FFF Enterprises or NuFACTOR. ©2007 FFF Enterprises Inc.

# Who Loves You When You're Down and Out?



"It's friendship," she mumbled, having dredged herself from the twilight of near slumber. "I thought of it right as I was falling asleep and I knew I had to call you. It's all about friendship, about helping each other, about supporting a caregiver while she fights for a child's diagnosis and then she turns around and helps you struggle with your own. It's about friendship. It doesn't matter how high up you are, how much you know, how great an advocate you are. At some point we all need help, we all need support, we all need friends. We can't do this stuff alone."

She's right, that friend of mine.

We'd talked earlier in the evening, about the need to find the positive in adversity, about stepping back from sorrow to see the beauty surrounding it, about hanging in there until the right thing happens, because it will, eventually it will, eventually.

But what of the frustration of fighting what seems an endless battle for fair immune globulin access, the risk of missed infusions, the anguish of your doctor finally saying, "I can't afford to treat you anymore," the fear of death?

These things can drag you down, down, down.

But still, she's right, that friend of mine.

She's right, because, if you look around, it is all about friendship.

Because when you're down, someone knows someone who knows an agency that will take on another abandoned Medicare patient.

Because when you're down, someone makes you take a break from advocating for other patients just long enough to advocate for your own care.

Because when you're down, someone knows someone who can play the denial appeals process like Yo-Yo Ma plays the cello.

Because when you're down, someone sends you a care package in the unfamiliar city to which you've uprooted your family for a hopeful surgery.

Because when you're down, someone who seems so much worse off says thank you, thank you for everything you do.

Because when you're down, someone knows someone who'll get you the IVIG for your next treatment even if you can't pay for it.

Because when you're down, a politician who doesn't even know you will mount his steed and clasp his lance to fight for you and others, yet again.

Because when you're down, a friend picks you up with a hug or a laugh or a good swift kick or a good shared cry, figuratively or literally.

Because, she's right, that friend of mine, we can't do this stuff alone. We need each other.

In these pages of IG Living, we sure hope you find a friend.

## IVIG Report Released

Heads up: The U.S. Department of Health and Human Services has released the long-awaited Office of the Inspector General report, "Intravenous Immune Globulin: Medicare Payment and Availability." To download a copy, visit [www.igliving.com](http://www.igliving.com).

## Welcome!

We are pleased to welcome Erika Lawrence, PhD, to our IG Living Advisory Board. Dr. Lawrence is a clinical psychologist, trained at the University of California Los Angeles, and an assistant professor in the Department of Psychology at the University of Iowa. She researches couple and family processes and functioning during times of stress and the relationships among physical health, psychological health and couple and family functioning. She also provides support to a family member with a chronic condition. Dr. Lawrence's training and personal experience will lend a wonderful addition to the review of editorial content of the magazine. We are most grateful for her generous contribution of her time, talent and sensitivity. ■

Kit-Bacon Gressitt, Editor

---

Please send your letters to the editor to [editor@igliving.com](mailto:editor@igliving.com).

# BAND-AIDES & BLACKBOARDS

By Joan Fleitas, EdD, RN

**B**and-Aides and Blackboards is a website packed full of resources for children and adults. Its intent is to sensitize people to what it's like growing up with medical problems. Too often, youngsters so affected must cope with the stigma of being "different" and with the condition itself. Teasing often accompanies this stigma and adds a layer of pain to their experience of childhood. Unnecessary pain. Pain that isolates. Pain that affects not only the children who look or act or even just feel different, but all of the children they interact with at school and in their neighborhoods.

## Learning From the Children

In the process of developing Band-Aides and Blackboards, I have been the student, and children have been my teachers. They have taught me what it's like for them to live in bodies that don't always behave, and what it's like for them to grow up in a world that is too frequently insensitive to their needs. They have spoken about a wide range of dilemmas. For some children, the dilemma is the ambivalence of enjoying extra privileges, yet hating the reason that they're offered. For others, it's the shame associated with medical diagnoses and a need that grows from that shame to keep hidden what is not directly observable. For many it's the ache to be popular and the belief that popularity is purchased with the coins of conformity. When that conformity forces children to ignore their need for medication and treatment, and when it demands of them a secrecy that consumes energy as it isolates, the price is very high.

The children who tell me their stories are children who are bothered to some degree by the social dimensions of their medical conditions. Many prefer not to think or talk about their differences. Acknowledging these differences seems to tattoo the reality of the disease, condition, illness, medical problem—you name it—on their identity. What they call it, then, becomes extremely important to them, with certain words having more power to isolate than others. As one child assured me, "I have this condition called diabetes. It's not a disease, because you can't catch it."

The most important thing I've learned from my conversations with children has been that they are, first and foremost, children. They have the same needs, joys, hurts, skills and misconceptions that all children share. Their chronic illnesses or other medical conditions are part of them, but do not define them. I hope that they will learn as they grow that they can be proud of who they are, and that what's going on with their health is a part of that pride, not something to be ashamed of.

## Telling Their Stories

On Band-Aides and Blackboards, I've tried to help children tell their stories, with hopes that, through their narratives, others will have an opportunity to walk in their footsteps and begin to understand. As I have learned from the Band-Aide experts, so too have I attempted to address the themes of their stories in educational and supportive ways. When they told me of teasing and exclusion, I developed a collection of pages on stigma. When they told me of their desire to be "just like everyone else... part of the gang,"

I ensured that the narratives they shared focused on their lives, not just the medical conditions that prompted their participation. When they told me that their friends focused on what they were unable to do, I created a hospital tour where the hospitalized children are the tour guides, the ones in the know, and where healthy, typically developing children learn from them.

The website has grown a great deal since I first published it. In addition to the stories, the site provides many resources for children, parents, health professionals and educators.

I hope that you will invite your youngsters to participate in this project. It's a project that allows them to share, with others, slices of their lives, as Kelly has here:

### Growing Up Sick

*My name is Kelly and I'm 19 years old (at least that's how old I was in 2001, when I wrote this story of mine). I've been sick since I was a little baby, but until a few years ago, I didn't know what in the world was causing me to feel so awful. Here's what it was like. Throughout my childhood, I caught one infection after another. It seemed like I always had miserable sore throats, muscle pain, exhaustion, headaches...and the list is even longer than that.*

*Needless to say, I missed a lot of school, but somehow I managed to keep up with my classmates. School was hard, as I couldn't always participate in gym or play games during recess. I went to more doctors than you could count, and they told my mother and me different things each time.*

*I had asthma among other things, and had to take medication before lunch every day. So did another kid in my class...at least we always went together. Even though the puzzle of my symptoms wasn't yet solved, the asthma provided an explanation to everyone about why I wasn't like my classmates. I have mostly outgrown the asthma now, but at the time it was my label.*

*My illness has affected my memory, and I don't have many memories of being a kid. I mean, I remember some important things, but some parts of my past are like blank pages. I do remember going to the doctor a lot, though, and being in a lot of pain. Now that's something I wish I had forgotten. There were times when I would lie on the couch, my shoulders and collar bone area hurting so badly that I wanted to scream.*

*It got worse when I was around 13. I was missing more school, and I had a headache that just never went away. I still have it as I type this story. I had even more symptoms, too; dizzy spells and blackouts that I've since learned were mini seizures. I had such*

*sore spots all over my body that if someone poked me in the back, I'd scream in pain.*

*My family told me I complained too much. My friends called me a wimp and a baby. One doctor said I was depressed. Another was convinced that I brushed my hair too much, so much, he thought, that it caused the blackouts and headache. What did he know? I couldn't even brush my hair some days because the pain was so bad.*

*When I was 14, I was incredibly depressed and sick of feeling sick. No one really believed me anymore because I complained so much. I was at my wits' end, so I swallowed a handful of painkillers. Luckily, I decided that no matter how poorly I felt, I couldn't imagine not being alive. So I called 911 myself. After that, I was in counseling for almost a year... now everyone (but me) was convinced that my illness was only in my head. When I would complain of pain, my mother would ask me if I needed an extra counseling session. See what I mean?*

*Thank goodness for my sister's doctor. She had been seeing her for arthritis, a problem that she's had since she was little. When I went into her office, she reviewed my blood test results. She pressed on some tender points on my chest and back, and asked about my fatigue. Then she sat back and told me I had something called fibromyalgia. Later I learned that I also have a disease called chronic fatigue immune dysfunction syndrome (CFIDS).*

*A name, a name, my illness had a name! It wasn't all in my head! But the name sounded so... ugly... I was ashamed. Today I can't believe I felt like this, but I was embarrassed to tell anyone what I had. Because my mother didn't feel that way, everyone quickly knew...*

To read more about Kelly and others' stories, visit Band-Aides and Blackboards at [www.lehman.cuny.edu/bandaides](http://www.lehman.cuny.edu/bandaides). May you enjoy your visit!

# Searching for Miller Fisher

By Jessica Schulman, PhD, MPH, RD

## Background

It was summer 2006 when Matt Johnson, enjoying a vacation in Greece with his wife, rolled his kayak and swallowed a mouthful of seawater. This is not unusual for a kayaker, but something in this mouthful proved virulent. Although Matt was a marathon runner and a cross-country skier, he was immediately stricken with intense stomach cramps and diarrhea. The symptoms remained severe for eight days after which they cut their trip short and returned home to Binghamton, NY. Three days after they returned home, his symptoms finally resolved. Matt quickly regained his strength and soon began his new job as deputy to the president of the State University of New York, Binghamton University (BU), where he also maintained a position as an associate professor of clinical psychology and a private practice as a therapist. He assumed that his infection had run its course, and that his illness was behind him. In fact, Matt felt great for exactly one day.

The next day, "I woke up feeling off... goofy... like I had slept funny." Throughout that morning, Matt began to experience double vision and odd tingling sensations in his legs. He found himself having to prop himself up so that he would not stumble or fall. He continued to feel odd when he met his wife, Deanne Westerman, for lunch later that day. Deanne is also a psychology professor at BU, studying human cognition and memory. When Matt shared his odd symptoms with her ("I feel like I'm drunk, that something is not right"), she became very concerned and, after allowing him to finish lunch, drove him straight to the emergency room (ER).

In the ER at Wilson Regional Medical Center, Matt felt a bit embarrassed, watching people with gunshot wounds being wheeled in on stretchers while he was complaining of double vision and some unsteadiness on his feet. Within a few hours of waiting in the ER, though, Matt's situation deteriorated. Gradually, he began to lose control of the muscles in his face. He began to slur his words. He lost the ability to blink. Afraid that his lungs might shut down, the physicians admitted Matt to the hospital's neurology unit.



## Diagnosis

Over the next 36 hours, Deanne worked with numerous consulting doctors to figure out what was happening. The first working diagnosis was that Matt was having a stroke, but, at 35 years old with below-average blood pressure, Matt did not fit the profile of a potential stroke victim. Nor did it appear that Matt had multiple sclerosis, myasthenia gravis, Lyme disease, or a brain tumor, all of which were considered as possible explanations. The medical staff considered Guillain-Barré syndrome (GBS), but Matt's symptoms were atypical. GBS usually starts with rapid onset of weakness—often in the legs—moving on to the breathing muscles and face. But Matt's first symptom was double vision, a problem with his cranial nerves, not his peripheral nerves. So the physicians began to search for an alternative diagnosis. Deanne, using her laptop computer and the hospital's wireless Internet connection, searched the web and recruited friends to help look for answers. It was one of those friends who suggested Miller Fisher syndrome, and indeed the doctors worked together as a team to confirm this diagnosis.

Miller Fisher syndrome, considered a variant of GBS, is characterized by abnormal muscle coordination, paralysis of the eye muscles, and absence of the tendon reflexes. Symptoms may also include generalized muscle weakness and respiratory failure, and are often preceded by an infection. Like GBS, Miller Fisher syndrome generally occurs shortly after an infection such as a sore throat or diarrhea. Some researchers speculate that the immune system produces antibodies that then turn on themselves, damaging the nervous system. This may be what happened to Matt. Even when he thought that he had recovered from his gastrointestinal infection, he was actually in the early stages of Miller Fisher syndrome. Most individuals with Miller Fisher syndrome have a specific antibody that can be used to diagnose the condition—a test that can take several days to conduct because of the rarity of the disorder.

### Treatment

In the interim, Matt's physicians ran with the presumed diagnosis of Miller Fisher syndrome and prescribed a five-day course of IVIG therapy. Within a few days of starting

the treatment, he was able to walk and his peripheral nerves recovered. Matt never lost respiratory function, and he credits this to the fact that he received timely and appropriate intervention.

Although he had avoided the worst, Matt's vision and cranial nerves remained affected for months after being discharged from the hospital.

He suffered from migraine headaches and severe fatigue. He slept for 23 hours a day, and walking to the kitchen for a bowl of cereal would completely exhaust him. His dogs, on the other hand, enjoyed Matt's illness quite a bit. He jokes, "I was living their life for a few months... sleeping all day and only getting up for dinner time."



### Coping and Recovery

How does a physically fit, athletic young man cope with a sudden and debilitating illness? "I had two things at my disposal," he says. "First, I have an amazing wife and family support system. Second, I work in a psychology department so I had friends and colleagues who were knowledgeable and willing to help. In fact, I added my friend who is a neuropsychologist to my health proxy so that he could brainstorm with my doctors and explain things to Deanne and me."

A crucial step, Matt says, was to understand the nature of his condition. Only then could he accept his circumstances and make preparations for what would be a long period of recuperation. "I went to the hospital literally on my lunch hour and thought that I would be back the next hour... once I learned what was wrong with me, I had to accept that I would be out for a few months." Making that mental shift gave him perspective. He tried not to worry about what was or was not getting done in his absence. "I changed my mind-set and, in a way, it was a positive experience because it made me understand how much I am cared for by my friends and family."

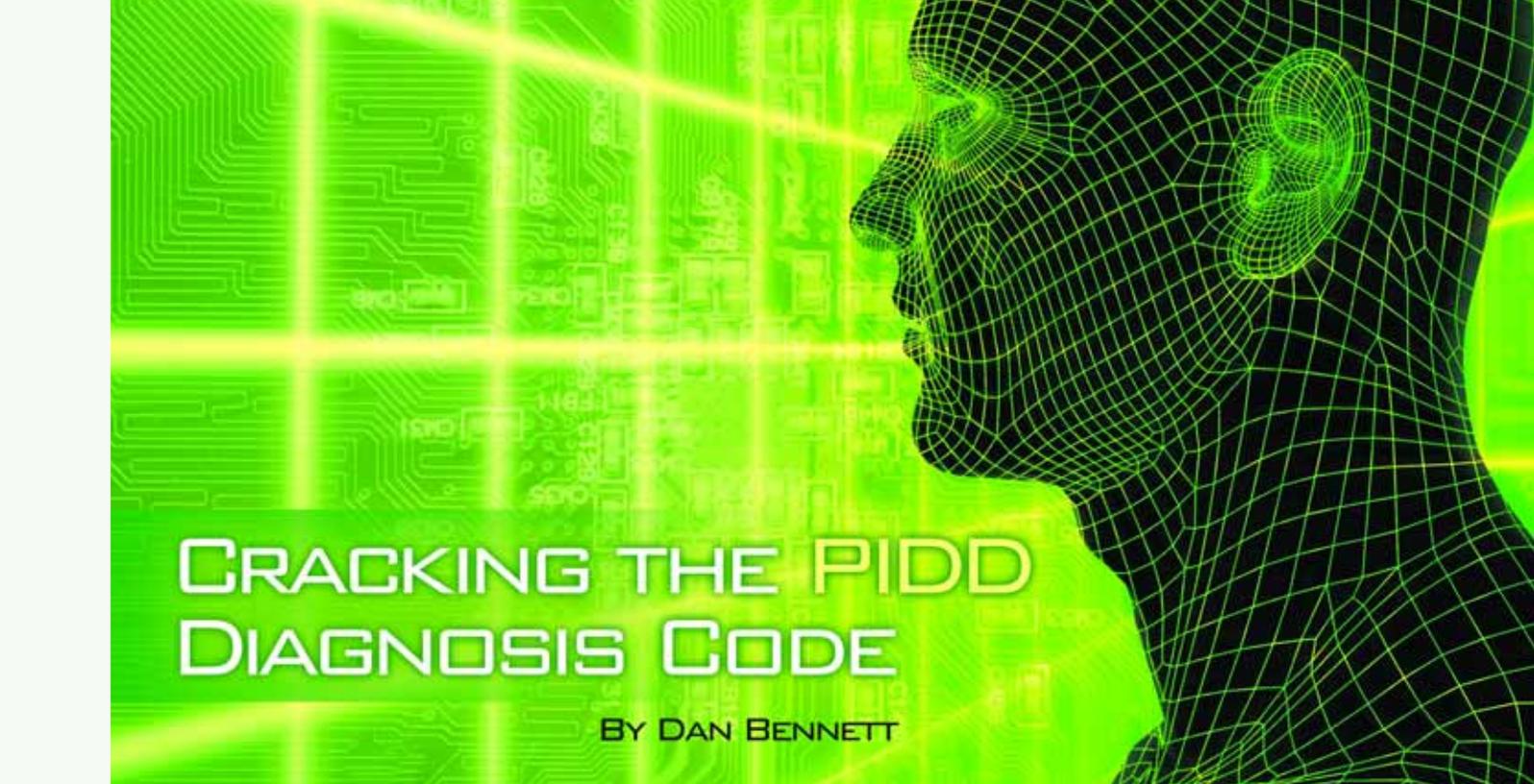
### Giving Back to the Community

Grateful for the IVIG that may have saved him from the worst of his disease, Matt was intent on contributing to the supply of immune globulin for others as soon as he was fully recovered. As it happened, though, Matt was prevented from donating his blood. Ironically, the obstacle was not the fact that he had Miller Fisher syndrome, but rather the fact that he had so recently received human plasma. Because IVIG is a plasma product, those who have received IVIG are required to wait several months before they can donate blood themselves. Ultimately, Matt will be able to donate plasma after all, which he finds satisfying. ■

### Resources

GBS/CIDP Syndrome Foundation: <http://www.gbsfi.com/>

National Institute of Neurological Disorders and Stroke, NINDS Miller Fisher Syndrome Information Page: [http://www.ninds.nih.gov/disorders/miller\\_fisher/miller\\_fisher.htm](http://www.ninds.nih.gov/disorders/miller_fisher/miller_fisher.htm)



# CRACKING THE PIDD DIAGNOSIS CODE

BY DAN BENNETT

Some medical diagnoses are easier to determine than others. Patients with primary immune deficiency diseases (PIDDs) know that a diagnosis is not always easy for their physicians. Many patients go several years and endure many tests before an accurate diagnosis arrives. Clearly, few things involving PIDD are obvious.

"This is a common story," said Steven Holland, a physician at the National Institute of Allergy and Infectious Diseases at the National Institutes of Health. "Like many things, florid cases are easy to identify, but subtle ones are hard. Also, the doctor—and the parent—are usually reluctant to think about the unusual, when the symptoms can also be due to usual things, such as a cough that can be a cold or pneumonia; a fever that can be a virus or an abscess. In my experience, the main challenges come for the families after the diagnosis. Most [PIDD] syndromes are relatively rare, and that means that the number of doctors and nurses who are familiar with them is small."

The result is often a delay in diagnosis and treatment. "These kids and adults are often stuck in emergency rooms or in new cities trying to get help on the one hand, and educate everyone around them on-the-fly about their disease," Holland said. "And if they get someone who is unaware of their own ignorance, the results can be devastating as well as frustrating."

Once a healthcare professional suspects PIDD, certain tests are suggested, but again, with PIDD those tests vary. "It all depends on the part of the immune system that is impaired," Holland said. "Usually I use the specific infections or syndromes—viral, bacterial, localized or disseminated—

to decide which area to test, such as antibody, neutrophils or cell-mediated. There are standard evaluations that typically look at antibody defects first—the most common causes—and then go down a specific pathway after."

Before the testing, there are the clues. The Jeffrey Modell Foundation publishes the 10 Warning Signs of PIDD (see the tear-off attachment). The Immune Deficiency Foundation ([www.primaryimmune.org](http://www.primaryimmune.org)) quotes a recent survey showing that only 12 percent of patients with a primary immune deficiency disease were initially diagnosed before age 1. Though the majority were diagnosed before reaching age 12, approximately 43 percent were not diagnosed until they reached adulthood. "Half of all persons with PIDD are not diagnosed until they are adolescents or older," the survey concludes. "One problem for early diagnosis is that the vast majority of patients have no family history of immune deficiency disease." Complications emerge from the lack of diagnosis. "The majority of patients suffered two or more hospitalizations before diagnosis," the survey states. "The majority experienced ear infections, bronchitis and pneumonias before diagnosis. Treatment significantly reduces the burden of disease."

IDF also provides clinical guidelines to physicians to help them recognize symptoms. According to an IDF publication, "The Clinical Presentation of the Primary Immunodeficiency Diseases (Physician's Primer)," "[a]lthough the initial description of patients with primary immunodeficiency diseases focused on their increased susceptibility to infection, these patients may also present with a variety of other clinical manifestations." The publication emphasizes that, "in some

patients, the noninfectious manifestations, such as autoimmune disease and/or gastrointestinal disease, may be the predominant clinical expression of their underlying immunodeficiency.”

The primer goes on to explain that an increased susceptibility to infection is the hallmark of primary immune deficiency diseases. “In most patients, this is manifested by recurrent infections. Often, individual infections are not more severe than those that occur in a normal host. Rather, the striking clinical feature is the recurring and/or chronic nature of the infections. Typically, the infections do not occur only in a single anatomic site, but usually involve multiple organs or multiple sites within the same organ.”

Heather Montgomery experienced symptoms as a young child, but it took several years for a proper diagnosis. She chronicled her experiences in a recent essay.

“When I was 18 months old, I was hospitalized with flu-like symptoms and a high fever,” Montgomery wrote. “Over the next four weeks, my condition got worse with each day. My platelet count and white blood counts went way down and I was put into isolation. The doctors were doing tests every day, looking for some disease that caused my illness.”

Troubled with a variety of ailments, Montgomery was kept away from other people, given antibiotics and placed on a special diet. This was her treatment for the next several years. “Back then, the medical community did not look for immune deficiencies in girls,” Montgomery wrote. “Therefore, I was tested for leukemia, lymphoma and other forms of cancer. I was also tested for different types of lung diseases.”

Finally, a diagnosis of agammaglobulinemia emerged. Later, complications with insurance and much-needed medical equipment became commonplace for Montgomery. Numerous medical ailments have followed, but Montgomery has pressed on with support from others. “I’m sure anyone who has had to deal with a rare illness knows how hard it is to deal with all of the complications that come from it,” she wrote. “I have been fortunate enough to have supportive friends and family members.”

Charlotte Cunningham-Rundles, a pediatric immunologist at Mount Sinai Medical Center, says delays in diagnosis are common. “The data says that there can be a long lag time, four to eight years in some cases,” Cunningham-Rundles stated. “Adults can look pretty well and still be immune deficient. Also, for adults, specialty care is divided up a lot, and maybe the overall theme is not being appreciated.” Among the most common tests, she said, are complete blood count (CBC), immune globulins and antibody tests.

For Lisa Russo, a long break in symptoms meant a delayed diagnosis. She was ill as an infant, but her childhood and early adulthood were mostly free of symptoms, with the exception of the common cold. Two years ago, at 42, Russo developed

bronchitis that wouldn’t clear up. “Within two days off of the antibiotics, I was getting sick again,” Russo said. “My physician has a friend who is an immunologist at Princeton, and after consultation they started testing my immune system. Now I’ve been on IVIG therapy for eight months, and the results have been amazing—no bronchitis since then.”

Mike Blaese, medical director of the Immune Deficiency Foundation, noted internists and family-practice physicians spend little time in immunology training related specifically to these diseases during medical school, so they often don’t consider more advanced illness that a specialist might suspect. One of the main challenges, Blaese says, is perception. With so few people, relatively speaking, diagnosed with PIDD, physicians perhaps tend to look past the possibility. Adding to the complexity is the fact there are more than 100 diseases under the PIDD umbrella. “What the IDF has been doing for 25 years is helping get the information out to healthcare professionals,” Blaese said. “There have been all sorts of publications and clinical care guidelines. With the work IDF has done, and with the work of the Jeffrey Modell Foundation and other organizations, there has been a real improvement in information awareness regarding these subjects.”

That wave of information is also intended for patients, with the parents of young patients a primary target of the ongoing campaign. “If nobody raises the suspicion, often the diagnosis will not happen,” Blaese said. “If parents suspect such a problem and can somehow get referred to one of the websites dedicated to these diseases, then they should make a printout, take it to the doctor and ask the question: ‘Is it possible my child has this?’”

Many parents can certainly relate to the frustration in achieving a diagnosis.

Marlo Wright’s daughter, Chelsea, began getting high fevers starting at 8 months old, along with double ear infections. Nine years, 14 surgeries, three near-death situations and 59 doctors later, a specialist in Ohio diagnosed primary immune deficiency. “There were always these what-ifs, but never a clear diagnosis,” said Wright, who lives in the Los Angeles area. “When I look back now, I can’t count the number of times I was called overreactive.”

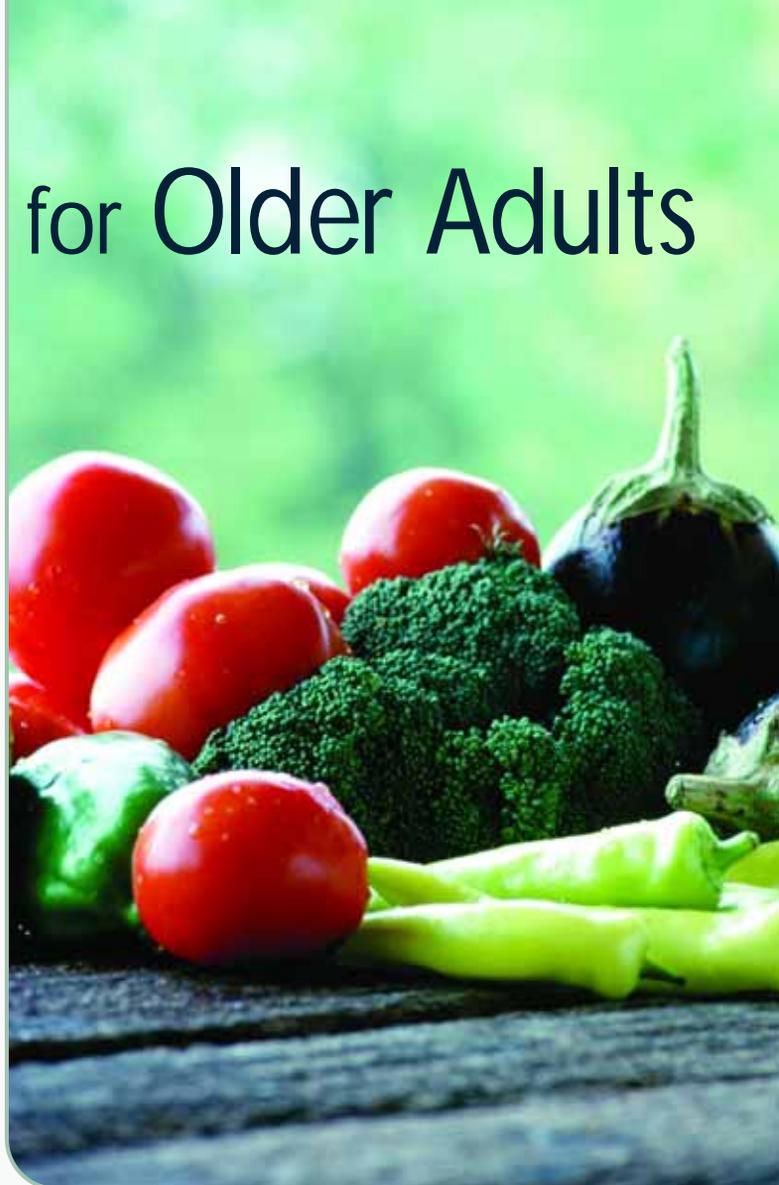
Last year, Wright went to a NICE Day event in Carlsbad, Calif., and was connected to the experts at UCLA, where the now 12-year-old Chelsea was diagnosed with common variable immune deficiency, lupus and juvenile rheumatoid arthritis. Chelsea now receives subcutaneous immune globulin treatment once a week. “I couldn’t be happier with the care she has now,” Wright said. “My advice to others is to never stop talking on behalf of your child, never stop asking questions. You are your child’s advocate.” ■

---

*Please see companion article, “Quest for the Elusive Diagnosis” on Page 27.*

# Optimizing Nutrition for Older Adults

By Jessica Schulman, PhD, MPH, RD



“Nutrition is one of the major determinants of successful aging,” according to the American Dietetic Association (April 2005).

Good nutrition supports health and independence by reducing the risk of chronic disease and slowing disease progression. Older adults who remain well-nourished are less likely to develop infections, have shorter hospital stays, heal faster and experience fewer complications than those who are poorly nourished. Unfortunately, a significant portion of adults 65 and older have suboptimal diets, lacking in key nutrients. A first step toward optimizing nutrition health in this population is to understand the changing dietary needs of older adults and the specific challenges that often prevent them from meeting those needs.

## Selected Vitamin and Mineral Needs That Change With Age

|                | Vit D (IU) | Vit B6 (mg/d) | Calcium (mg/d) | Sodium (g/d) | Chloride (g/d) |
|----------------|------------|---------------|----------------|--------------|----------------|
| <b>Females</b> |            |               |                |              |                |
| 31-50 yrs      | 200        | 1.3           | 1000           | 1.5          | 2.3            |
| 51-70 yrs      | 400        | 1.5           | 1200           | 1.3          | 2.0            |
| > 70 yrs       | 600        | 1.5           | 1200           | 1.2          | 1.8            |
| <b>Males</b>   |            |               |                |              |                |
| 31-50 yrs      | 200        | 1.3           | 1000           | 1.5          | 2.3            |
| 51-70 yrs      | 400        | 1.7           | 1200           | 1.3          | 2.0            |
| > 70 yrs       | 600        | 1.7           | 1200           | 1.2          | 1.8            |

## Nutrition Goals for Older Adults

Like everyone else, older adults should make every effort to eat a healthful diet and, when it is advisable, to follow the Dietary Guidelines for Americans. Although recommending general nutrient goals for older adults is difficult—because many require specialized diets—for most seniors the Food Guide Pyramid ([www.mypyramid.gov](http://www.mypyramid.gov)) is a useful starting point. What follows is a summary of the Dietary Guidelines for Americans with key recommendations for older adults.<sup>1</sup>

## Key Recommendations:<sup>2</sup>

### Calories From Nutrient Groups

- Eat a variety of nutrient-dense foods and beverages within and among the basic food groups while choosing foods that limit the intake of saturated and trans fats, cholesterol, added sugars, salt and alcohol.
- Meet recommended intakes within energy needs by adopting a balanced eating pattern, such as the USDA Food Guide Pyramid.
- People over age 50: Consume vitamin B12 in its crystalline (i.e., fortified foods or supplements).
- Older adults: Consume extra vitamin D from vitamin D-fortified foods and/or supplements.

<sup>1</sup> Used with permission from Florida International University, Miami's National Resource Center on Nutrition, Physical Activity and Aging.

<sup>2</sup> See Dietary Guidelines for Americans 2005, Key Recommendations for the General Population, <http://www.health.gov/dietaryguidelines/dga2005/recommendations.htm>.

## Weight Management

- To maintain body weight in a healthy range, balance calories from foods and beverages with calories expended.
- Those who need to lose weight: Aim for a slow, steady weight loss by decreasing calorie intake while maintaining an adequate nutrient intake and increasing physical activity. Consult a healthcare provider about weight loss strategies to ensure appropriate management of other health conditions.

## Physical Activity

- Older adults: Participate in regular physical activity to reduce functional declines associated with aging and to achieve the other benefits of physical activity identified for all adults. May need to consult with a healthcare provider before participating in these levels of activity.
- To reduce the risk of chronic disease in adulthood: Engage in at least 30 minutes of moderate-intensity physical activity, above usual activity, at work or home on most days of the week.
- To help manage body weight: Engage in approximately 60 minutes of moderate-to-vigorous-intensity activity on most days of the week while not exceeding caloric intake requirements.

## Food Groups

- Consume a sufficient amount and variety of fruits and vegetables while staying within energy needs.
- Consume 3 or more ounce-equivalents of whole-grain products per day, with the rest of the recommended grains coming from enriched or whole-grain products.
- Consume 3 cups per day of fat-free or low-fat milk or equivalent milk products.

## Fats

- Keep total fat intake between 20 percent to 35 percent of calories, with most fats coming from sources of polyunsaturated and monounsaturated fatty acids, such as fish, nuts and vegetable oils. Consume less than 10 percent of calories from saturated fatty acids and less than 300 mg/day of cholesterol, and keep trans fatty acid consumption as low as possible.

## Carbohydrates

- Choose fiber-rich fruits, vegetables and whole grains often.

## Sodium and Potassium

- Consume less than 2,300 mg (approximately 1 tsp of salt) of sodium per day.
- Older adults and individuals with hypertension: Aim to consume no more than 1,500 mg of sodium per day, and meet the potassium recommendation (4,700 mg/day) with food (potassium-rich foods, such as fruits and vegetables) unless otherwise directed by your physician.

## Food Safety

- Older adults and those who are immunocompromised: Do not eat or drink raw (unpasteurized) milk or any products made from unpasteurized milk, raw or partially cooked eggs or foods containing raw eggs, raw or undercooked meat and poultry, raw or undercooked fish or shellfish, unpasteurized juices, and raw sprouts. Only eat certain deli meats and frankfurters that have been reheated to steaming hot.

When dietary intake is not varied, older adults may benefit from a low dose multivitamin and mineral supplement. While therapeutic doses of certain nutrients are sometimes warranted, seniors with medical conditions should always consult with their doctor and pharmacist before taking any dietary supplements.

## Fluid Intake

There is no consensus on exactly how much fluid older adults should consume. However, in general a 150-pound adult requires approximately 2 quarts, or 8 cups, of water per day. This daily amount includes fluid from beverages and certain foods such as soups. Water needs vary widely depending on metabolic state and health condition. For example, those who are very active, live in hot climates, experience gastrointestinal problems (e.g., inflammation, constipation, diarrhea, vomiting), or have fevers will have increased fluid needs. For every degree Fahrenheit above normal, fluid needs increase by about 7 percent or about one-half cup of water. In contrast, those with congestive heart failure, hypertension, kidney or liver failure may have reduced needs for water. If you have a medical condition, it is important to follow your physician's recommendations for fluid intake.

## Restrictive Diets

Therapeutic diets are designed to improve health status, but restrictions have the potential to create new problems. Whenever a special diet is being considered, patients ➤

### Nutrition Health Checklist

1. I have an ongoing health problem that affects my diet.
2. I have lost my appetite and/or often skip meals.
3. I have a chewing or swallowing problem.
4. I have nausea, diarrhea or constipation.
5. I drink less than 6 cups of liquid a day.
6. I am on a special diet that was ordered by my doctor.
7. I take more than three different medications.
8. I lost weight without trying. Or, I gained too much weight without trying.
9. I am unable to shop, cook or feed myself nutritious meals.
10. I don't have enough money to buy nutritious foods.
11. I eat alone most of the time.

*This checklist is intended to raise awareness of potential nutrition concerns among older adults. This is not a clinical diagnostic tool.*

and caregivers should ask: Is a restrictive diet necessary? Does the diet offer health benefits that justify its use? Will the senior benefit from this restrictive diet?

Dietary restrictions that are recommended for younger adults are not always beneficial for older adults. Although studies show that dietary excesses and inactivity results in obesity and impairment of everyday functioning, being overweight is not associated with decreased life expectancy for seniors age 75 and up. For this reason, the American Diabetes Association suggests that a sensible approach to helping seniors achieve nutrition goals may be to make medication changes, rather than enforce food restrictions such as "no concentrated sweets."

In another example, researchers concluded that elevated cholesterol levels for heart disease may not be critical among the elderly. Therefore, nutrition experts explain that "the appropriateness of low-cholesterol diet prescriptions for older adults in long-term care facilities is questionable... Although practitioners should be cognizant of cardiac problems, malnutrition is a more serious threat for most older adults than elevated cholesterol."<sup>3</sup> In some cases, a practitioner may suggest a more liberalized diet to improve intake, rather than enforcing strict diets.

In general, it is important to be open-minded when assessing risks versus the benefits of therapeutic diets. An unacceptable or unpalatable diet will not improve food and fluid intake and may worsen undernutrition and poor health outcomes. Qualified professionals can help you to determine the need for nutrition therapy based on each person's individual medical condition, desires and rights.

### Obstacles to Adequate Nutrition for Older Adults

Paradoxically, during a stage of life when certain nutrient needs increase, food and fluid intake often decreases. Why? One reason is that older adults experience changes in physiological functions, such as muscle mass, metabolic rate, gastric activity, sensory perception, fluid and electrolyte regulation, frequency of illness and other social determinants that often lead to poor nutrition status. Sometimes medications that are intended to help can harm nutrition status. Vitamin B12, for example, maintains healthy nerves and blood but is particularly sensitive to the effects of age and medication use. (See <http://www.nlm.nih.gov/medlineplus> or <http://www.pdrhealth.com> for a comprehensive list of drug-nutrient interactions.)

Inadequate fluid intake is another common problem among seniors. Reasons for this problem may include difficulty preparing or eating foods, changes in the social environment, medication effects, mobility problems and cognitive changes, among other causes. In addition, seniors often have a reduced thirst sensation that interferes with their ability to meet daily fluid intake goals. Understanding how changes associated with aging affect food and fluid intake can help partners, caregivers and practitioners recognize the unique needs of older adults and develop strategies for achieving individualized nutrition goals.

### Troubleshooting and Caregiver Support

Often, the burden of achieving the dietary goals of older adults falls squarely on the shoulders of family caregivers. They may receive little guidance or support as they plan and prepare meals, shop, assist with meals and, when needed, administer tube- or intravenous-nutrition feedings. In a medical setting, trained volunteers can take up some or all of these tasks. Whether the senior is hospitalized or in a home setting, caregivers are encouraged to advocate for their loved ones and not be afraid to ask for help with nutrition concerns.

How can family members and caregivers assist elders in improving nutrition health? A first step is to understand the types of meals that are consumed and how symptoms are related to timing of meals and medications. Seniors and their caregivers may find it useful to record their observations in a log, review them over time, and make dietary adjustments as needed (e.g., coordinating pain medicine on a schedule that reduces discomfort during mealtimes).

To improve intake, involve seniors in decisions about their eating schedule, food choices and dining locations, and create senior-centered meals. Sometimes, it is necessary to

<sup>3</sup> American Dietetic Association, Dec. 2005.

make arrangements for informal caregivers or volunteer services to help arrange meals, create a pleasant eating experience and coach or assist with eating and drinking beverages. One study found that seniors who were given friendly verbal prompts to encourage fluid intake several times a day were more successful at meeting daily fluid intake goals. Offering between-meal frozen juices, slushes, etc., is useful during sick days. Of course, providing seniors with culturally appropriate or preferred nutritious beverages and foods improves intake as well. Adding more spices, stronger odors and flavor enhancements to foods may be helpful for those with sensory impairment.

Modifying food texture and consistency can help older adults with chewing and swallowing problems, and should be done under professional guidance. If nutrition health is at risk (see the Nutrition Health Checklist), speak with your primary care physician about the need for a registered dietitian, social worker, speech therapist or other types of professional support.

## Resources and Programs

Planning an appetizing and nutritious meal that meets the complex needs of older adults is not an easy task. A list of educational resources is provided to assist readers with meeting nutrition goals and promoting well-being and independence for seniors.

## Links to Nutrition Health

- Dietary Guidelines for Americans, 2005 Edition: <http://www.health.gov/dietaryguidelines>
- Drug Nutrient Interactions (MedlinePlus & the Physician Desk Reference): <http://www.pdrhealth.com> or <http://www.nlm.nih.gov/medlineplus>
- Electronic menu planner: <http://hp2010.nhlbihin.net/menuplanner/menu.cgi>
- Modified Food Pyramid for Older Adults (Tufts): <http://nutrition.tufts.edu/consumer/pyramid.html>

## Nutrition, Aging and Assistance

- <http://nutritionandaging.fiu.edu>
- The American Dietetic Association or to find a registered dietician in your area: <http://www.eatright.org> or 800-877-1600
- USDA: MyPyramid personal nutrition tracker: <http://www.mypyramid.gov>

## Nutrition Assistance Programs

- Community-based services can be located through the Eldercare Locator: [www.eldercare.gov](http://www.eldercare.gov)  
Toll-free: 800-677-1116 9:00 a.m. to 8:00 p.m. (ET)

## Examples of Medications That May Reduce Vitamin B12 Absorption

- Acid- and H2-reducing agents (omeprazole: Prilosec®, Losec®; lansoprazole: Prevacid®; rabeprazole: Aciphex®; pantoprazole: Protonix®, Pantoloc®; esomeprazole: Nexium®, Tagamet®)
- Allopurinols (Aloprim®, Zyloprim®)
- Antibiotics (neomycin; aminosalicic acid: Paser®)
- Anticonvulsants (primidone: Mysoline®)
- Antiepileptics (phenytoin: Phenytek®, Dilantin®)
- Barbiturates (phenobarbital: Luminal®)
- Biguanides (metformin: Glucophage®), antiretrovirals (zidovudine: AZT, Combivir®, Retrovir®)
- Nitrous oxide anesthesia
- Resins (colestipol: Colestid®; cholestyramine: Questran®)

Monday–Friday. TDD/TTY Service: Access your relay service or dial “711” for your operator. Instruct the operator to connect you to Eldercare Locator: 800-677-1116

- Meals on Wheels Association of America (MOWAA) provides home-delivered meals services to older adults, homebound, and at-risk individuals. For help, or to give a gift, go to: <http://www.mowaa.org> 703-548-5558
- The National Family Caregiver Support Program: <http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/carefam.asp>. Click: “Help! Where to Find It”
- The U.S. Department of Agriculture (USDA) Nutrition Assistance Programs: <http://www.fns.usda.gov/fns> and <http://nutritionandaging.fiu.edu>

## References

1. American Dietetic Association (ADA). Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care Volume. *J Am Diet Assn*. Dec 2005;105:1955-1965.
2. ADA. Position Paper of the American Dietetic Association: Nutrition Across the Spectrum of Aging. *J Am Diet Assn*. Apr 2005;105:616-633.
3. *Dietary Guidelines for Americans 2005*, Key Recommendations for the General Population: <http://www.health.gov/dietaryguidelines/dga2005/recommendations.htm>.
4. National Resource Center on Nutrition, Physical Activity & Aging | Florida International University: <http://nutritionandaging.fiu.edu>.
5. Niedert, Kathleen, and Dorner, Becky, eds. *Nutrition Care for the Older Adult: A Handbook for Dietetics Professionals Working Throughout the Continuum of Care*. Chicago: American Dietetic Association, 2004.

*Editor's note: The information provided in this article outlines general principles of healthy nutrition for the purpose of education only and is not intended to be used as a substitute for medical advice. Always consult with your physician, or a credentialed nutrition expert, before initiating a specialized diet or using dietary supplements.*

# Lessons From Kris, J.J. and Shaggy at Northwest Folklife

By Mark T. Haggard

When you cross the Idaho state line, there is a sign saying, "Welcome to Idaho, please turn your clocks back ten years." The people in Idaho just like things the way they are. If it isn't broken, don't fix it. Cut your lawn to three-quarters of an inch. Keep your dog on a leash. Wheel your garbage can back into your garage before noon on trash day. Do what you're told; be good citizens of your community; conform. We get it.

Last year, our primary immune deficient kids, Caleb and Molly, were referred to the University of Washington in Seattle and the foremost immunologists in the world. Since then, we have stuffed our children into an airplane and taken them to three appointments in the Pacific Northwest, enjoying the Emerald City each time. We have connected with Kris, an IVIG specialist who lives there, who has become a valuable resource, friend and travel agent for our family. And, we have learned that the time change between Idaho and Washington is much more than one hour.

For our last trip to see Auntie Kris and the fine physicians at Children's Hospital Seattle, we decided to take an extra day to enjoy the best Seattle has to offer: the Space Needle, Pike's Fish Market and, of course, Ivar's Acres of Clams.

So, after chasing our well-loved suitcases around the baggage claim, and doing everything we could to keep our kids off the carousel, we gathered around the family cell phone to announce to Auntie Kris that, "We're heeeeeerrrr!"

As my wife, Cheryl, listened, the look on her face told me that we were going to be on our own for a bit. The taste in my mouth went from deep-fat-fried halibut to disappointment.

"Two hours," Cheryl announced solemnly. "She's in a meeting with a doctor, but wants us to meet her at the Space Needle in two hours."

Two hours? What were we going to do with our three kids for two hours after 90 minutes on an airplane? Our 8-, 7-, and 4-year-old children were in need of a lap or two around Puget Sound. We couldn't keep them cooped



up in a hotel room; the monkeys needed to be let out of their cage.

"Aha," I said, "we'll call a cab company and take our own tour of the city."

After a quick phone call and an "Absolutely not!" to the kids' requests for Starbucks Double Shot Espresso Mocha, our cab driver, J.J., greeted us with a hearty, "Hello." J.J. delivered us to the Seattle Center, home of the Space Needle, in record time, and along the way, he entertained the kids with lessons in Somali.

The Seattle Center was more crowded than I remembered the first few times I had visited. People kept asking us if we wanted to register to vote and pleaded with us to sign a petition to have Washington use only "clean, renewable fuel sources." Hundreds of tents were set up with peddlers selling a variety of wares. One had Cantonese pot stickers—hard to find in Idaho. One tent was selling "feng" to complement your "shui." It took every bit of my backwoods strength and self-control not to purchase Cheryl a purse and matching belt made from hemp.

Unbeknownst to us, J.J. had dropped us off in the middle of Northwest Folklife, a gathering of body hair

and granola like none these Idahoan eyes had seen before. Most of the people, male and female, were in their 50s and had ponytails that fell beyond the collars of their tie-dye T-shirts. Cheryl tapped my shoulder as we approached a Zen meditation booth and whispered, "I regret shaving my armpits this morning."

We continued our trek, desperately trying to find a place for three children, just 40 minutes removed from having their "seat belts fastened, tray tables stowed, and seats in the full upright position," to run and jump and tackle each other. But where?

A Gen Xer who looked like Shaggy from "Scooby-Doo" occupied one curb strumming "Imagine" on the sitar. On another curb, a wannabe Billy Joel played political satires on a piano with "Impeach Bush" bumper stickers on its side. Two college-age buddies blew into matching 6-foot-long horns, prompting me to yell "Ri-cola!"

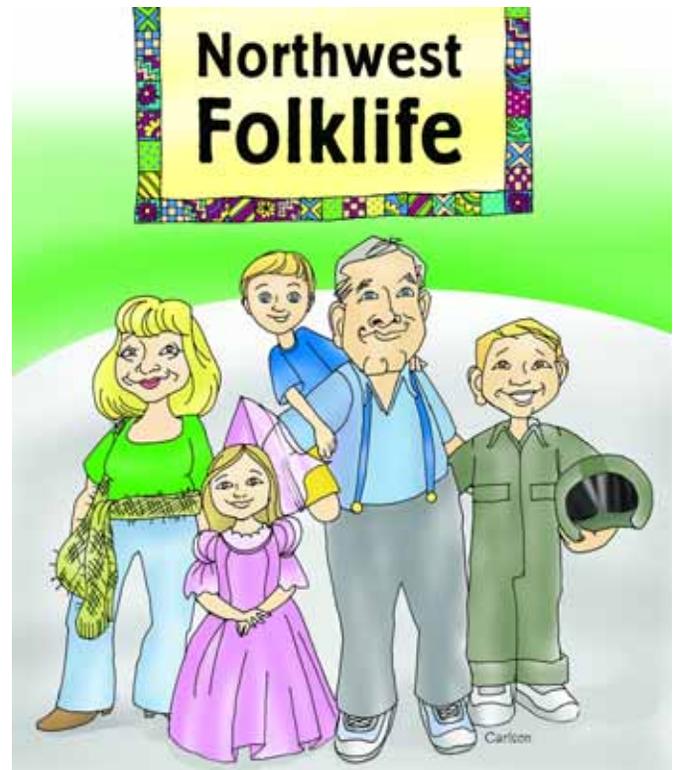
Meanwhile, we all had strange cravings for double-bacon cheeseburgers, and we were aching to see someone "normal" again—like J.J., our Somali cabdriver.

It was when we saw a 60-something, goofy-grinned female-type crooning "The Impossible Dream" while accompanying herself on the accordion that we determined Kris could not get to us soon enough. Cheryl desperately grasped for her cell phone from inside her dead cow purse and frantically punched in Kris' number.

"Hey, uh, Kris," Cheryl's voice sputtered like the engine of a 1967 VW Bug, "can you put your appointment at U-Dub on hold and come rescue us from Alice's Wonderland?" The look on Cheryl's face told me that our knight in minivan armor was only minutes away.

To Seattle urbanites, we must have looked like Bo, Luke and Daisy Duke jumping through the windows of the General Lee as we piled into Auntie Kris' van. After a quick getaway from Northwest Folklife, Auntie Kris took us out for something more our speed: red meat. Along the way, Cheryl and I got a good chuckle at the antics of the city folk. There are not many people in Boise who can play "Imagine" on the sitar or "The Impossible Dream" on the accordion. As for clean, renewable energy sources? Well, most of the people in Idaho still burn their trash.

The next morning, on our way to Children's Hospital, I saw a bumper sticker that etched perspective in my Idaho mind-set: "Great People Are Not Conformists." I looked at my children, with still undiagnosed immune disorders, and noted my respect for their dreams: Caleb wants to be a U.S. Navy Blue Angel and Molly, a Disney princess.



Both are determined to be great people, and in their own way they are not conformists. They suffer from a disease that is like very few others. They receive a medicine like few others. They kick, scream and fight to avoid their needle sticks, but with teary eyes tell their nurses "thank you," after getting them.

We in the immune-compromised community are great people. Just like the people at Northwest Folklife who felt that it was necessary to find their voices, we too have had to find ours. We do not back down when our insurance companies refuse to pay for IVIG. We are continually in the eyes and ears of our legislators, fighting for continued access to IVIG. We are vocal in informing the public of our rare disorders, even when they say, "Well, you don't look sick." We stand up and speak, because few other people will speak for us. We refuse to conform; we cannot. Cures will not be found in conformity.

So, our journey to the Emerald City ended much like it began: learning how to say "goodbye" in Somali and chasing children around the baggage carousel. We returned to our "turn your clocks back ten years" state with a new vision to see our kids live healthy, productive lives, despite the fact that their mom is the only woman in Idaho who owns a hemp purse and matching hemp belt. ■

# IG Reimbursement



## Q&A

By Michelle Vogel and Kit-Bacon Gressitt

**W**e continue to receive questions about reimbursement for intravenous immune globulin (IVIG) homecare treatment. While homecare is a strong preference for many patients, because of the flexibility and freedom it can offer, the Medicare Modernization Act changes to IVIG reimbursement have affected reimbursement for the homecare setting. Understanding current coverage for your disease state for IVIG therapy in the home will help you make a more informed decision if you are contemplating a move to homecare.

### Several patients have asked: Do you have to be homebound to receive IVIG in the homecare setting?

No, you do not need to be considered homebound to receive Medicare reimbursement for your IVIG therapy. However, although Medicare pays for the IVIG product in the homecare setting, Medicare does not cover the nursing services and equipment for administering IVIG in the home. Regardless, there are homecare companies that find the reimbursement rate adequate to accept homecare patients for IVIG therapy.

It is important to understand what Medicare will knowingly cover, so let's review by disease state:

- If you have a primary immune deficiency disease (PIDD), your IVIG product is covered under Medicare Part B and cannot be covered under Part D.
- If you have a diagnosis other than PIDD that Medicare covers, including chronic inflammatory demyelinating polyneuropathy (CIDP), myositis, myasthenia gravis and other covered diseases, you should be covered under Medicare Part D.

All patients are encouraged to have secondary insurance plans—not including Medigap—that should cover the nursing services and the medical equipment needed to deliver your IVIG.

The current reimbursement under Medicare Part D is better than Part B, so patients who have a diagnosis that allows for their IVIG to be covered under Part D will likely be able to find a homecare company that will provide service.

Remember: If you are a PIDD patient and have found a homecare company that will accept you as a patient, it is very important that you ask the following question:

Are you billing my IVIG under Medicare Part B?

If the answer is “no” and the company tells you that they can bill under Part D and Medicare will cover it, be careful; this is not what the law states!

**Maureen, a homecare patient, has been receiving IVIG for about five years and has a private insurance policy. Maureen recently realized that her usual home-care company was no longer providing the treatment and she is under the care of a new provider. She has received a bill for her out-of-pocket expenses for two months for approximately \$25,000. She can't afford to continue her treatments and is considering stopping her infusions altogether. What can she do?**

Maureen's previous homecare provider was not billing her for out-of-pocket expenses, most likely because the company was a participating or preferred provider with her insurance company. The new homecare company is not a preferred provider, and Maureen was never notified about having a choice about who would provide her homecare.

Patients must understand their policies, know if their providers are part of their networks and be alert to unexpected changes in their providers.

Ask questions if you start receiving your IVIG from a different company. This is a very costly treatment, and you need to know how to work with your insurance company to make your out-of-pocket expenses as minimal as possible.

In Maureen's case, we are taking it one step at a time.

1. Maureen is requesting a case manager to be assigned to her.
2. Maureen is contacting a homecare company that contracts with her health insurance company.
3. Maureen is obtaining copies of all the bills that have been submitted by the new homecare company to her insurance company. We will be able to look at the bills and make sure that they have been submitted correctly.
4. Maureen is requesting that her insurance company send copies of her explanation of benefit (EOB) forms to her. With these EOBs, we will be able to clearly see what this new homecare company has covered and what they have denied.

We'll report back when we have a resolution to Maureen's case.

If any of our readers are having similar problems, please make sure that you request a case manager with your health insurance company. Some health insurance companies may say that there is a waiting list, so ask that your name be put on the list. Make sure that you are receiving copies of the bills all of your providers submit to your insurance company, including to Medicare. Finally, make sure that you are receiving EOBs in the mail. If you are not, contact your insurer and request that you receive all of your EOBs. This will help you determine if a bill has been denied and for what reason. Remember, if you have been denied coverage by your insurance company, always appeal. Insurance companies count on a certain percentage of patients accepting their decisions without appealing. Most people do win their appeals, although it will take some time, good documentation and a lot of patience.

**Liz, from Ohio, asked: Can a hospital deny treating neurological patients with IVIG, unless the patients receive a second opinion from a neurologist on staff?**

Yes, hospitals can deny patients IVIG. Throughout the IVIG access crisis, we have seen a resulting prioritization of IVIG use, based on diagnosis, typically giving higher priority to on-label indications. On-label indications are those diagnoses for which IVIG is approved by the Food and Drug Administration.

Unfortunately, there are no on-label indications for any of the neurological disorders. However, this does not automatically result in a denial of coverage.

In Liz's case, the hospital's neurologist was opposed to the use of IVIG for neurological disorders and was denying patients access to the therapy. This is not appropriate. Therefore, if you find yourself in a situation where you are told that you need a second opinion in order to receive your infusion, even though you have a prescription for your IVIG from your physician, discuss the situation with your treating physician and work with him or her to find a second opinion to support your diagnosis and treatment plan. If an institution requires a second opinion, you should be allowed to go to any specialist of your choice.

Ultimately, regardless of diagnosis and insurer, your IVIG therapy coverage may come to depend on your persistence, the support of your treating physician and patience.

Please contact IG Living if you need assistance:

[editor@igliving.com](mailto:editor@igliving.com).

# Homskool Mi PI DD Kidz?

By Cheryl Haggard



I am often asked why I do not home-school my three children, two of whom have been diagnosed with primary immune deficiency disease.

"Aren't you afraid they are going to catch something really awful?" people ask.

"No," I quickly respond, "the bugs at school are nothing compared to the germ farm on the bottom of your purse."

I don't mean to be snippy. In fact, I have the utmost respect for my friends who have chosen to home-school. Quite frankly, my home-schooling buddies are some of the bravest and most brilliant people on the face of the

earth. It's just not for me, and it'd be a safety hazard to my kids' maturing brains.

There is one reason and one reason alone I don't home-school the kids: Mathematics does not add up in my universe.

It took me seven times to pass the math section of the CBEST (California Basic Education Skills Test). Maybe you didn't read that right, I said *basic* math, not advanced, not even anything beyond sixth grade. Counting is not one of my strengths.

My kids learned to count by pushing numbers on hospital elevators. I'd go so far as to slap the hand of a

stranger reaching for the elevator keypad and admonish the unsuspecting victim with, "You're interrupting our counting lesson."

Recently, I made an attempt to explain "one-third" to my kids, using a simple pie chart. My crude drawing of a misshapen pizza had one vertical line and a diagonal line and then quickly dissolved into half of a peace sign. To this day it draws jeers from my husband and has forced my children into fraction therapy.

The nail in the coffin of the Haggard Homeschool International happened within the tender first days of kindergarten for Calvin.

Kindergarten homework is hard, especially when you are in the middle of infusing IVIG into one child and desperately trying to keep the baby sister from feeding out of the dog dish.

It was dreadfully painful for me to help Calvin logically place a lost teddy bear into its proper home on the pattern grid while attempting to domestically coordinate the family. So painful, in fact, I had to excuse myself numerous times to go set my eyes back into their sockets. Yet, after an hour and a half of logical thinking kindergarten-style (and frying my 30-something brain cells), Calvin slipped his completed bear graph back into his Superman backpack and we celebrated our victory over a hearty Sloppy Joe.

The next day Calvin returned from school and dumped the contents of his backpack onto the kitchen table.

"How'd school go today?" I asked with confidence as my common denominator.

"You got a note," my budding mathematical genius replied.

Maybe a commendation from Calvin's teacher, I thought.

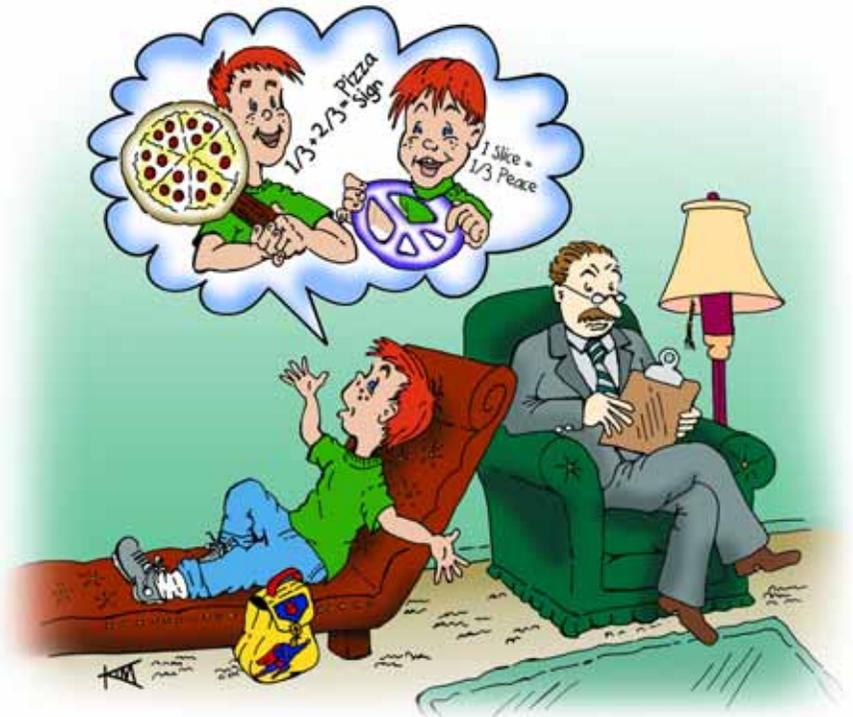
I unfolded the paper to find the following letter penned for my eyes only:

*Dear Mrs. Haggard,*

*Thank you for making an effort to help Calvin with his math homework.*

*Please don't do it anymore.*

*Sincerely yours,  
Mrs. Brown*



Despite my math deficiency, I think my PIDD kids have made out pretty well. They have had to endure the School of Hard Knocks, and those lessons can only be mastered in the classroom of life. The compassion they feel when they see someone sick or in pain is the direct result of the difficult physical tests they have endured.

I recently observed our daughter, Molly, offering comfort to a puppy who obviously had just had surgery (the cone protruding from the poor fella's head was my first clue).

"What happened to your puppy?" Molly sweetly asked.

"Oh, Brutus had to have a little surgery on his eye," the pooch's owner explained.

"Oh, I know how that feels. It hurts bad," Molly sympathized. "I hope Brutus gets better soon!"

Brutus' mom looked my way and said, "What a sweet child! You must home-school."

If only she knew. ■

# Where Does My Immune Globulin Come From?

By Kit-Bacon Gressitt

Where does my immune globulin come from? At IG Living, we hear this question a lot, and its frequency is understandable because so many of our readers infuse immune globulin (IG) into their bodies. What's surprising is that we don't hear the question more often—from everyone whose health depends on IG products.

Perhaps folks are practicing the philosophy of "ignorance is bliss"—for instance, there's nothing more effective than too much information to ruin a good hotdog—but ignorance does not serve the immune globulin consumer well. In fact, understanding the source and creation of IG products explains a lot of otherwise mysterious things: why IG products are so expensive, why the supply is sometimes tight or even short, why safety is so critical to IG products and their recipients and why recipients are so dependent on the thousands of people who donate their plasma—as volunteers or for compensation.

Which brings us to the topic of this, the first in a series of articles on the origins of IG products. Through the series, we will tell the complex and compelling story of how IG starts with one person's blood and ends up as a fractionated and purified plasma product in the body of another.

## It All Starts With Plasma—and Its Donors

"I've been donating blood for eight years." Why? "People are struggling, and I'm able to give something to help."

This is Heather, 30 years old and a little reticent about her reason for being at her local blood donation center on this particular Friday morning. Heather has been through a rigorous screening process, including responding to a long, invasive list of questions about her health and



Heather giving blood

drug use, travels, sexual history and more—and a physical examination to check her vital signs and arms where veins are accessed. She does all of this every time she gives blood, a donation that takes about an hour.

And, every time Heather or any other donor gives blood or a blood component such as plasma, it is tested for a laundry list of recognized indicators of blood-borne illnesses, including hepatitis, HIV and West Nile virus. Any donation that tests positive is destroyed.

Heather now reclines in a chair, well-designed for the purpose of extending an arm, accessing a vein and drawing a unit of blood.

"I try to get friends to come with me, but..." She shrugs.

Donating blood can seem a little intimidating if you've never given before, and needles are never fun. People must donate for other more compelling reasons.

Heather looks away as the phlebotomist sticks a needle in her vein, and her blood wends its way through the attached tubing and into a clear bag that gradually takes on the rich scarlet hue of whole blood.

The blood will be spun in a centrifuge at a processing laboratory, separating the red blood cells, platelets and plasma. Each blood component will be used to help heal another person in need—in need of red blood cells, perhaps to improve the oxygen-carrying capacity of a trauma patient's body fluids; in need of platelets, perhaps to prevent bleeding associated with chemotherapy; in need of plasma, perhaps to replace coagulation factors lost during open-heart surgery.

Some of the plasma collected by the center will be fast-frozen and shipped to the facilities of a plasma products

manufacturer. Such plasma is referred to as “recovered plasma,” because it is salvaged from whole blood. The plasma is mixed or “pooled” with plasma from thousands of other donors and made into immune globulin, coagulation factors and albumin through a process known as fractionation, which separates the various proteins found in human plasma.

Heather is told of the very ill patients who might receive what becomes of her plasma, and she realizes her donation has more meaning than she had ever known. Then she shares why she came today, of all possible days, to donate her blood.

“It’s actually my birthday today, and I get to give back to others!” She smiles a wide and wonderful grin.

Those around Heather take in a collective breath, acknowledging the poignancy of her generous birthday gift.

“Very cool!” They all agree.

### Recruiting Plasma Donors

Unlike whole blood donors, plasma donors spend an extra 30 to 60 minutes while their blood is drawn, centrifuged to separate the plasma from the other components, and the red blood cells and platelets are returned to them.

Although the process takes longer, plasma-only donors give more plasma at each sitting than whole blood donors and they can donate more regularly, up to twice a week, compared with a limit of once every two to three months for whole blood. But the extra effort involved in donating plasma can be a deterrent to prospective donors.

“It seems harder to get men of a certain age group. Younger people are more open to doing it; women are more open,” one plasma recruiter explains. He’s been at

it long enough that he can tell pretty quickly who is going to give and who isn’t.

There are hurdles, but he shares with potential plasma donors the sense of urgency he feels, especially when there’s a plasma shortage. “If I can help make the gateway into the donation a little more comfortable, then I feel good about it.”

Comfortable or not, donor recruitment is essential to creating plasma products, including immune globulin:

It can take as many as 3,000 individual donations to treat one patient with immune globulin for a year.

To overcome the challenges to donor recruitment, some plasma centers offer donors a small payment, and, given the demand for plasma products, both paid and volunteer donors are needed. In fact, all five of the U.S. immune globulin manufacturers buy some or all of their raw plasma from collection centers that pay donors.

Plasma safety concerns are addressed through extensive donor screening and plasma testing—and the exclusion of risky donors. Yet, if too many donors are ruled out, the plasma supply is reduced, which in turn reduces the availability of plasma products such as immune globulin. If less product is available, patients go without treatment.

It seems a bit of a Catch-22, attempting to balance product safety with supply, but there is a potential solution: encouraging more plasma donors by educating them about the patients they can help.

### Revealing the Joy of Giving

“One of the major causes of IVIG access problems is the lack of raw material.” Judi Miller is the vice president of medical affairs for Octapharma USA, a plasma products manufacturer.

Approximately 60 percent of the U.S. population is eligible to donate blood, but only 5 percent of those who can, do. Many non-donors say they never thought about giving plasma or they’ve never been asked.

“Now we *are* asking,” Miller says. We’re letting people know just how much their donations are needed. It’s very simple: To increase the availability of IVIG, we need more plasma and that means we need to recruit and retain more donors.”

To help meet this need, Octapharma has created “Vein-to-Vein,” a program to educate blood and plasma centers and the public about the need for and benefits of plasma donation. Judi hopes that increased understanding of how donated plasma saves and enhances the lives of seriously ill patients will increase the number of donors.

“When prospective donors realize the number of life-saving therapies that can be produced from each liter of plasma, we hope they will be motivated to become long-term donors.”

Maybe on her next visit to a blood center, Heather will find her friends more inclined to join her. ■

---

*Editor’s note: To donate blood or plasma, look up a blood center near you at [www.aabb.org](http://www.aabb.org) or [www.americasblood.org](http://www.americasblood.org) or search the Internet for “plasma donation.”*



# Wisconsin Takes the Lead in Testing Early SCID Diagnosis

By Jeff Siegel

Shortly after Amarion Webster was born, he had an ear infection. In rapid succession, he next developed pneumonia, then acid reflux, then he broke out in eczema, and then pneumonia again. By the time Amarion was 6 months old, he had been sick so often that he weighed just 11 pounds. Along the way, he had seen a raft of doctors, including a dermatologist, gastroenterologist and immunologist.

“And when he was born, we thought he was a healthy baby,” says Amarion’s mother, Patricia Webster.

In fact, he was far from it. About four months after he was born, Amarion was finally diagnosed correctly—with severe combined immune deficiency, or SCID, perhaps the most lethal of all of the immune deficiency diseases. SCID, marked by a severe lack of T cells that fight infection, is sometimes referred to as the “bubble boy” disease, after a Texas child who lived most of his 12 years of life in a sterile plastic enclosure. Whatever it’s called, SCID is normally fatal if not diagnosed early enough, and early SCID diagnosis is usually elusive, because the disease is so rare.

But all that may be about to change.

A pilot program in Wisconsin is under way to see if it’s possible to detect SCID within days of a child’s birth. The program is a collaboration between the Wisconsin State Laboratory of Hygiene, Children’s Hospital of Wisconsin in Milwaukee and the Jeffrey Modell Foundation. If the program is successful, it could spare babies such as Amarion from misdiagnosis and save their lives. Armed with a correct diagnosis, doctors can perform a bone marrow transplant, which has a 95 percent success rate if done in the first three months of life.

“There has been feverish interest to go forward with this screening,” says Fred Modell, a co-founder of the Jeffrey Modell Foundation, which initiated and helped fund the pilot program. “We think this is going to be successful, whether we find out that one baby or two babies—or four or eight are identified with SCID.”

## SCID Basics

SCID, although apparently genetically linked, is quite rare, affecting one in 50,000 to 500,000 babies, according

to the National Institutes of Health. Some doctors actually say that number may be too low, since many babies die before they can be diagnosed, apparently killed by one of the infections or other ailments that the weakened immune system can’t fight.

SCID causes a defect in the white blood cells that normally help protect the body from viruses, bacteria and the like, resulting in a reduction in the production of T cells that the body uses to fight infection. Without enough T cells, SCID babies usually get serious infections in the first few months of life, including pneumonia, meningitis and blood infections, and these infections are often fatal.

“A bone marrow transplant is an effective treatment for SCID,” says Duke University’s Rebecca Buckley, MD, one of the leading researchers in the field. “The problem has always been not just identifying children with the disease, but doing it quickly enough so that a bone marrow transplant is possible. Most SCID babies are too sick after the first three to six months for the transplant to be successful.”

In the last decade, a blood test has been developed that accurately measures the number of T cells, based on genetic material called T cell receptor excision circles, or TRECs. TRECs seem to predict how well the body will manufacture T cells. Researchers at the National Human Genome Research Institute in Bethesda, Md., discovered that healthy babies have 1,020 TRECs per 3-millimeter blood spot, compared to less than 30 for SCID babies.

“But there had not been a practical, cost-effective way to run that blood test on most newborns,” says Modell. Although babies are routinely screened for a variety of illnesses with a blood test shortly after birth, it wasn’t possible to perform the SCID test with the techniques and equipment most hospitals use for newborn blood screening.

All this has changed in the last couple of years, thanks to techniques developed by Jennifer M. Puck, MD, at the Genome Research Institute. Her work, say researchers, led to a way to use the routine hospital blood test to measure the number of TRECs. This innovation should allow physicians to know within days, as opposed to months, if at all, whether a baby has SCID. And, if the baby does, a bone marrow transplant can be performed quickly, perhaps

even before the baby suffers its first SCID-related infection.

"If we can identify SCID very, very early—and I hope we can—that will make it easier to diagnose and to get treatment and to ultimately save lives," says John Routes, MD, who will oversee the pilot program. Dr. Routes is a professor of pediatrics at the Medical College of Wisconsin and the medical director of Allergy and Clinical Immunology at Children's Hospital of Wisconsin. "We're going to go full steam ahead on this. The faster we can get it going, the better."

### Understanding the Study

According to Dr. Routes, Wisconsin volunteered to do the study because it had the money, the facilities at the state hygiene lab, and a respected and sophisticated newborn testing program. "We thought it was ideal for us," says Dr. Routes. "This is a progressive state, and we were actually very intrigued to be part of the pilot study."

Among the other goals of the program:

- To get a better idea of how rare SCID is. About 70,000 babies are born annually in Wisconsin, so the testing is expected to find one or two babies, or even none at all, who suffer from the disease. If, on the other hand, the study finds three or four, researchers will have something to ponder about the incidence of SCID.
- To lay the groundwork for testing programs for other immune diseases. Modell says that if the SCID program proves successful, it could help speed up research into testing for a number of the 140 genetic defects included in primary immune deficiencies. The goal there, he says, is to be able to diagnose the disease within one to two years instead of the six to seven it takes now, thereby getting patients on proper therapy sooner and saving patients from the long-term damage that often results from delayed diagnosis and treatment.
- Raising SCID awareness among doctors and parents. If both groups know that babies can be tested for SCID, they are more likely to ask about it and spread the word. This, says Webster, is something she found surprising—that so many parents she met didn't know what their children were facing. "They need to stay involved with everything that's happening," she says.

*"If we can identify SCID very, very early—and I hope we can—that will make it easier to diagnose and to get treatment and to ultimately save lives."*

~ John Routes, MD

- Improve SCID testing. Eventually, says Dr. Buckley, it might be possible to perform a test for SCID within minutes of birth, using the baby's umbilical cord blood. "That's one reason why I'm so enthusiastic about what's happening," she says. "We might even be able one day to do a diagnosis in utero."

The Wisconsin program will cost \$500,000—half paid by the state, half by the Jeffrey Modell Foundation. Many states, says Dr. Buckley, didn't have the money. This is one of the paradoxes of the U.S. healthcare system. The new method of testing should cost about \$8 a child, and will determine if the baby needs a bone marrow transplant—at the cost of \$100,000-plus. Compare that to the \$1 million it often costs to treat a SCID baby in its first eight to 12 months of life, if the baby survives.

"In fact, one of the many good things that could come out of the Wisconsin program," says Modell, "is that this kind of math will make more sense to more states that could start their own testing programs." California, Maryland, Massachusetts, Missouri, New York, North Carolina and Ohio are considering similar pilot efforts. The state health agencies met last fall in Atlanta with officials from the Centers for Disease Control, and Modell says the mood was quite optimistic.

That is good news to Webster, who understands not only the physical and emotional difficulties of SCID, but the financial ones as well. She didn't work

for 18 months so she could care for Amarion, which wasn't easy on her husband and two other sons, 17 and 19.

If the Wisconsin program is successful, it could protect countless families from the wrenching experience the Websters had between Amarion's birth and his successful diagnosis and treatment.

"If we can do this at birth, it would just be so much better," she said. Amarion did eventually have a successful bone marrow transplant, but it was touch and go getting there. "Amarion would get sick, and then you'd have to wait for him to get better to have the transplant, and then he'd get sick again."

Screening at birth would indeed be better for everyone. ■

## Immune Globulin Studies Focus on Reducing Side Effects

By Alma Morales

If you ask patients on immune globulin (IG) to name what's most distasteful about receiving infusions, their most common answer is the side effects, often including headaches, nausea, rash and fever—none of which is any fun.

Luckily for patients, doctors and clinical researchers are studying ways to minimize the side effects of regular IG infusions, both intravenous and subcutaneous.

One medical center making strides in the quest to improve IG therapies, including the reduction of side effects, is the University of California, Los Angeles (UCLA) Medical Center and David Geffen School of Medicine. The Medical Center currently has more than five immune globulin studies in planning or implementation phases sponsored by various IG manufacturers.

"For Southern California, we are the largest facility for clinical research and applications of immunoglobulin," said Maria Garcia-Lloret, MD, assistant professor in pediatrics at UCLA Medical Center.

"We are a Jeffrey Modell Foundation Center of Excellence for diagnosis and treatment of immune deficiency," Dr. Garcia-Lloret continued. "That is essentially our area of expertise."

Robert Roberts, MD, PhD, and clinical associate professor at UCLA, explained: "Most immunoglobulin studies are not testing an experimental drug. The studies focus on lowering the side effects."

In addition to being unfamiliar with the potential positive results of these studies, many patients are not aware of the benefits of participating in IG studies. Because IG is not an experimental new drug, patients don't have to worry about extreme side effects or not knowing what to expect. Instead, they are able to remain on their routine IG therapy schedule and dosage, although they may be switched to an alternate product. As part of the bargain, they have a few extra forms to complete with each infusion, and they are asked to keep a diary to track side effects.

"We don't change their dosage; we just change the product," Dr. Roberts explained. "Because of this, most patients experience few side effects."

While the treatment may not change much, there's a



*Dr. Roberts examines Preston Martin*

great added benefit of participating in studies: the amount of additional medical attention a study patient receives. "Patients get a little more care by being involved in the study, because they are closely monitored," Dr. Roberts said, and the care is free throughout the length of the study.

One patient currently involved in an IG study, 17-year-old Preston Martin, is already seeing an improvement in the side effects he used to experience. Martin receives IG treatments to treat hypogammaglobulinemia, and he is now in his second year of the study. He has received a total of 13 infusions, one every 28 days. One of the main improvements Martin appreciates is the absence of headaches after his infusions. "On the previous drug, within three days [of infusing], he would get headaches," Denise Martin, Preston's mom, recounted.

"They were like mini-migraines," Preston explained.

As with all clinical studies, success is largely based on the participants' willingness to take the time to record their symptoms and follow through during the entire course of the study. In fact, finding enough dedicated participants for a study is one of the main reasons some studies never come to completion.

According to Dr. Roberts, UCLA is always looking for new study participants, and the studies are ongoing, so patients can simply call to be added to the list of prospective participants. Most studies last six to 24 months, depending on the patients' reactions to the product and their schedule of availability.

The benefits of a little extra paperwork—free medical care and treatment with already-approved IG products—surely make the UCLA studies worth a phone call for more information. ■

### For More Information

If you are interested in participating in an IG clinical study at UCLA (or in learning about other studies), visit [http://www.igliving.com/web\\_pages/resources\\_mrs.html](http://www.igliving.com/web_pages/resources_mrs.html) or contact Dr. Robert Roberts at 310-825-6777.

For information about the Jeffrey Modell Foundation Centers for Excellence, visit <http://www.info4pi.org>.



# Quest for the Elusive Diagnosis

By Lauren Gerstmann, MPH

“One of the most widespread diseases is diagnosis.” —Karl Kraus in *Beim Wort genommen* (1955)

IVIG, or intravenous immune globulin, is a very versatile drug. It has been explored as therapy for such diverse conditions as autoimmune disease, immune deficiencies, cancer, neurological conditions and entrenched infectious diseases. IVIG seems to regulate the immune system and to suppress harmful inflammation.

But, in some ways, its versatility can create challenges for the patients and doctors who use it. Since IVIG has so many uses, and because it treats conditions that may also be treated with other drugs, doctors may have trouble deciding when to use it, and insurance companies may be reluctant to approve it. This article will set out some of the most common diagnoses that are treated with IVIG, and it will briefly tell the stories of people who have struggled with these conditions.

The patients' stories illustrate the potential benefits of IVIG and the

barriers to having IVIG prescribed and covered by public and private insurers. However, it is important to note that each patient's situation is unique, and IVIG is one of several therapeutic options that can be considered for immunological conditions. Ultimately, treatment choices should be made with the patient's physician.

## The Many Uses of IVIG

IVIG can be used to treat both autoimmune disorders and immune deficiencies. Your immune system can malfunction if it becomes overactive and begins attacking your own tissues or nerves (an autoimmune disorder) or it can be lacking a key component to protect you from disease (an immune deficiency). More than 80 autoimmune disorders have been identified! Diagnosis can be time-consuming and difficult, as many of these disorders have overlapping features. But, a correct diagnosis is critical in order to be sure that you receive appropriate treatment. Similar

problems with diagnosis affect people suffering from primary immune deficiencies. According to the Immune Deficiency Foundation, ➤

## How Are Immunity and Autoimmunity Related?<sup>2, 3</sup>

- One possibility is that immune deficiency makes it harder for the body to rid itself of dead cells, and perhaps those dead cells can contribute to development of an autoimmune response.
- Another possibility is that healthy immature B cells learn to tolerate their own antigens by being exposed to those antigens. If an immune-deficient person does not produce those antigens, and the B cells do not become tolerant, an autoimmune reaction can develop.
- A third possibility involves patients who have low numbers of lymphocytes circulating in their bloodstream (lymphopenia). Lymphopenia may allow T cells to proliferate in an abnormal way, predisposing patients to an autoimmune disease.

<sup>1</sup> US Department of Health and Human Services: National Institute of Health: Autoimmune diseases coordinating committee, NIH Publication 03-5140, December 2002. [http://www.niaid.nih.gov/dait/pdf/ADCC\\_Report.pdf](http://www.niaid.nih.gov/dait/pdf/ADCC_Report.pdf).

<sup>2</sup> Looney, RJ and Uzel, G, *Immunodeficiency Disorders and Autoimmunity* Presentation at the AAAAI Annual Meeting on February 25, 2007.

<sup>3</sup> Uzel, G, *Immunodeficiency Disorders and Autoimmunity* Presentation at the AAAAI Annual Meeting on February 25, 2007.

it can take up to nine years after you start having symptoms for you to get a correct diagnosis of a primary immune deficiency.<sup>4</sup>

One complication is that many people have multiple diagnoses. The relationship between immune deficiencies and autoimmune disorders is still unclear, and there does not appear to be a unifying theory to explain the entire relationship. The bottom line is that if you have an immunological disorder, be it an autoimmune disease or an immune deficiency, you should educate yourself about IVIG and talk with your doctors about it.

## The Most Common Condition Treated With IVIG

### Primary immune deficiency disease (PIDD)

#### Ian's Story:

Primary immune deficiency diseases are disorders in which part of the body's immune system is missing or

does not function properly. The World Health Organization currently recognizes more than 100 primary immune deficiencies. They are caused by an inherent or genetic defect in the immune system and are not a result of injury, infection or drug use.<sup>5</sup> By far, the most common PIDD is common variable immune deficiency (CVID)<sup>6</sup>

Ian<sup>7</sup> was diagnosed with CVID in November of 2004, after a series of illnesses. As an infant, he was hospitalized for a week with a rotavirus, and his mom, Valerie, thought that they might lose him. She knew something was wrong because Ian was always sick. He would go on antibiotics for an ear infection in his right ear, and without notice his left eardrum would rupture. Between the time Ian was 1 and 3 years old, he had eight sets of tubes surgically placed in his ears to drain the infections. He saw an allergist/immunologist in Washington, who couldn't figure out what was wrong and referred the family to Children's Hospital in Washington. The specialists there concentrated on ruling out cancers (such as leukemia) and cystic fibrosis. Relieved to dodge these bullets, the family moved to California, where Ian did very well—for about nine months. Suddenly, they were back to square one when Ian ended up in the hospital for a week and a half with symptoms similar to viral meningitis. Once again, Valerie thought "we were going to lose him." Three months later, the scenario repeated. The doctors in California repeated all of the same tests that had been run in Washington with no new findings. Eventually, Ian's pediatrician began

her own investigations. She decided to run immunological studies, to consult with other specialists, even to get in touch with the Centers for Disease Control. Once she began to close in on the answer, Ian's pediatrician referred him to experts at UCLA.

It took a long time, and several false starts, for Ian to get the correct diagnosis. But, now that he has overcome these barriers, Ian receives IVIG therapy every three weeks. He is a very active kid and a skilled hockey player! Ian told me that since he has been diagnosed and treated, he feels "way better, and can do all kinds of stuff."

Note: See the companion article, "Cracking the PIDD Diagnosis Code" on Page 8.

## Examples of Some Autoimmune Conditions Treated With IVIG

### Myositis

#### Kristin's story:

Myositis is swelling and loss of muscle. A small amount of myositis can be a normal result of exercise. But, in its extreme form, myositis becomes an inflammatory myopathy, an autoimmune disease where the immune system attacks the body's own normal, healthy tissue through inflammation or swelling. All of the diseases that fall under the general term myositis, including dermatomyositis (DM), polymyositis (PM), inclusion-body myositis (IBM), and juvenile forms of myositis (JM or JPM), can cause muscle weakness,

## Diagnosing PIDD

<http://www.emedicine.com/med/topic1161.htm>

### Physical Examination

- Unexplained frequent and severe illnesses of infectious origin

### Lab Studies

- Blood work, including immunoglobulin levels, IgG subclasses and measurements of specific antibodies

### Imaging Studies

- X-rays and/or CT scans may be useful to monitor lung involvement

<sup>4</sup> Immune Deficiency Foundation Releases National Statistics on the Treatment of Primary Immune Deficiency Diseases: Results Show Average Time From Onset of Symptoms to Diagnosis a Staggering Nine Years [http://www.primaryimmune.org/news/survey\\_release.pdf](http://www.primaryimmune.org/news/survey_release.pdf).

<sup>5</sup> Immune Deficiency Foundation: *What Is a Primary Immune Deficiency Disease?* [http://www.primaryimmune.org/pid/whatis\\_pid.htm](http://www.primaryimmune.org/pid/whatis_pid.htm).

<sup>6</sup> Park, CL, *Common Variable Immunodeficiency*, eMedicine—last updated 8/10/2006 <http://www.emedicine.com/ped/topic444.htm>.

<sup>7</sup> Ian and his mother, Valerie, were interviewed by the author on 2/16/2007.

but each type is different<sup>8</sup>; and therapy varies depending on the cause of the myositis, i.e., IVIG is likely not effective for all types of myositis.

Kristin's<sup>9</sup> symptoms began slowly, and then suddenly. When she was 25 years old, she began to feel worn out. Tiredness was easily explained by her busy workload, and she started

## Diagnosing Myositis

[http://www.myositis.org/about\\_myositis/getting\\_diagnosed.cfm](http://www.myositis.org/about_myositis/getting_diagnosed.cfm)

### Physical Examination

- Muscular weakness

### Lab Studies

- Aldolase Test
- Antinuclear Antibodies (ANA) Test
- Creatine Phosphokinase Test
- Sed Rate (ESR)

### Procedures/Imaging Studies

- Muscle biopsy
- Magnetic resonance imaging (MRI)
- Electromyogram (EMG)

canceling plans with her friends so she could sleep through the weekend. She felt as though someone was constantly pushing her down. Her doctor listened to her concerns. He ran basic blood work and checked her thyroid, but found nothing wrong. Then her feet began to swell. Again, there was no explanation. Kristin was able to function through the fatigue and discomfort, so she stopped questioning her symptoms. By the time she turned 27, Kristin could no longer keep up with her 60-year-old co-workers

when they went for lunchtime walks. One day when Kristin was out shopping, she realized she could no longer walk at all. Convinced she had the flu, she went home to recuperate. But, the next weekend, she could hardly "walk, open my mouth or even use my right arm too much. ...My [calf] muscles, jaw muscles and right forearm muscle [were] so tight that I [could] hardly move them. So, as you can imagine, walking, talking, eating, standing, writing... all the everyday stuff [was] extremely painful." She went to the emergency room, but all the doctors could tell Kristin was that she "had a lot of inflammation." They gave her anti-inflammatories and sent her home. When she followed up with her regular doctor, and he realized how inflamed she was, he began to suspect myositis. He checked her creatine kinase levels (a lab test that measures muscle damage), ordered a muscle biopsy, and sent her to a rheumatologist.

Although some types of myositis are treated with IVIG, Kristin uses methotrexate (a drug used in treatment of cancer and autoimmune diseases that works by inhibiting the metabolism of folic acid). Methotrexate, while effective, can—with long-term use—cause damage to the lungs and liver.<sup>10</sup> Three years after she was diagnosed, Kristin began to research IVIG therapy, but the expensive treatment was not covered by her insurance company. Since her muscle deterioration was under control, neither Kristin nor her rheumatologist wanted to take on the challenge of

protesting the insurance company's decision. In a difficult situation like this, it might be a good idea to get a second opinion to make sure that you are getting the most effective, but also the safest treatment. Kristin would still like to try IVIG if changes in her insurance policy allow it.

## Idiopathic thrombocytopenic purpura (ITP)

### Jeff's story:

Idiopathic thrombocytopenic purpura is a rare autoimmune bleeding disorder that is a disease of exclusion. In other words, if you have ITP, your immune system attacks your platelets (a type of blood cell), causing them to be destroyed in your spleen. But, with ITP, you have no known disease process to explain why your immune system is targeting your platelets. ITP can lead to abnormal bruising and anemia.<sup>11</sup>

ITP is difficult to diagnose, because there are many disease processes that could cause you to have thrombocytopenia, or low levels of platelets in your blood. In order to diagnose ITP, you need to rule out all the other potential causes of thrombocytopenia, such as leukemia, myelophthisic marrow infiltration, myelodysplasia, aplastic anemia, pseudothrombocytopenia<sup>12</sup> due to platelet clumping, or adverse drug reactions.

In Jeff's<sup>13</sup> case, his mother, Judy, a new nurse, came home one day to find her 13-year-old son covered in hives "15 inches in diameter. They looked like they were filled with blood, and he was having trouble breathing." ➤

<sup>8</sup> The Myositis Association: *About Myositis*: [http://www.myositis.org/about\\_myositis/index.cfm](http://www.myositis.org/about_myositis/index.cfm).

<sup>9</sup> Interviewed by the author on 2/22/2007. Please also visit her blog, "Muscular Mayhem" at <http://www.ksite.blogspot.com>.

<sup>10</sup> RxList: [http://www.rxlist.com/cgi/generic/mtx\\_wcp.htm](http://www.rxlist.com/cgi/generic/mtx_wcp.htm).

<sup>11</sup> WebMD: Idiopathic Thrombocytic Purpura: <http://www.webmd.com/hw/anemia/nord258.asp>.

<sup>12</sup> Sandler, GS & Shexneider, K, *Idiopathic Thrombocytic Purpura*, on eMedicine- updated 5/30/2006. <http://www.emedicine.com/med/topic1151.htm>.

<sup>13</sup> His mother, Judy, interviewed by the author on 2/16/2007.

Jeff had been frequently sick as a child, suffering repeated colds, bronchitis, even pneumonia. But, his doctors had always assured Judy that the illnesses were unrelated. When he developed the hives, Jeff was treated at a local hospital with IV cortisone for a week to open his airways. Eventually, he was transferred to Loyola Medical Center, where he saw several specialists, including a hematologist, who eventually concluded that there was no identifiable cause for his disease, and so defined it as ITP.

Although the cortisone worked, Jeff would have recovered more rapidly with IVIG therapy. But, he was diagnosed too long ago. Even though IVIG use was first documented in the 19th century, it wasn't part of ITP treatment until 1981.<sup>14</sup> Thirty years after Jeff's bout with ITP, he was also diagnosed with common variable immune deficiency (CVID). He has been living with the chronic illnesses associated with CVID for so long that he may never fully recover. But, at last he is receiving IVIG treatments that are improving his quality of life.

## Diagnosing ITP

<http://www.emedicine.com/med/topic1151.htm>

### Physical Examination

- Evidence of unusual bleeding or bruising

### Lab Studies

- Bloodwork to characterize blood cells, check for autoimmune markers, and rule out Evans syndrome and HIV

### Procedures

- Bone marrow aspiration and biopsy

## Chronic inflammatory demyelinating polyneuropathy (CIDP)

### Kathy's story:

Chronic inflammatory demyelinating polyneuropathy is a rare neurological disorder that may first manifest as progressive difficulty in walking. CIDP causes swelling of nerve roots and destruction of the fatty protective covering (myelin sheath) over the nerves. It is a progressive disorder that causes weakness, paralysis and/or decreased motor function. It can also cause other nerve damage resulting in numbness and tingling. After onset, the progress may be rapid or sporadic, and the end disease-state may vary in severity. Usually CIDP affects people in the same way on both sides of their body. CIDP differs from other similar neurological disorders in that the patient has not necessarily had a viral infection within the three months before the symptoms present. In most cases, there is no family history of other similar disorders or other nerve diseases (such as polyneuropathy).<sup>15</sup>

Like Kristin, Kathy<sup>16</sup> had trouble getting the appropriate diagnosis and getting her insurance to pay for her IVIG. Kathy had been experiencing pain for years that she and her doctor attributed to her weight and her arthritis. In 2000, while she was moving into her new two-story home in Houston, she started having a lot of trouble with the stairs. She kept losing her balance, was weak, and she had a lot of numbness and pain in her foot. She went to see a pain doctor who diagnosed her with a peripheral neuropathy. But none of

the medication the pain doctor prescribed worked. So Kathy saw a neurologist who recognized the signs of CIDP. Kathy underwent a biopsy and nerve testing. IVIG, neurontin and Lyrica (drugs that treat neuropathic pain), and methadone (a synthetic opiate) were the only things that helped Kathy. Her doctor would not allow her to use steroids because she was borderline diabetic, and it would have upset her glucose balance. When she switched her insurance to Medicare, she could no longer go to her clinic for IVIG treatments. Kathy was directed to the local hospital, but they did not have sufficient IVIG to treat her, and she was told to simply stop her treatments. At that time, she moved to Washington, where she is able to continue her IVIG. Because Kathy was willing to move in order to get her treatments, her condition is stabilized today.

## Diagnosing CIDP

<http://www.emedicine.com/neuro/topic467.htm> &  
<http://www.gbsfi.com/aboutcidp.htm>

### Physical Examination

- Difficulty walking
- Abnormal reflexes/sensations

### Lab Studies

- Spinal tap
- Blood work to look for markers of infection and autoimmune antibodies
- Urine test
- Genetic testing

### Procedures/Imaging Studies

- MRI
- Electromyogram (nerve testing)
- Nerve biopsy

<sup>14</sup> Scheinfeld N & Godwin J, *Intravenous Immunoglobulin*, on eMedicine- last updated 10/11/2006: <http://www.emedicine.com/med/topic3546.htm>.

<sup>15</sup> Chronic Inflammatory Demyelinating Neuropathy on WebMD: [http://www.webmd.com/hw/brain\\_nervous\\_system/nord903.asp](http://www.webmd.com/hw/brain_nervous_system/nord903.asp).

<sup>16</sup> Interviewed by author on 2/22/2007.

## Guillain-Barré syndrome (GBS)

### Aidan and Matt's stories:

Guillain-Barré syndrome (GBS) is sometimes considered to be an acute form of CIDP. The body's immune system begins attacking the nerve system, and progression can be alarmingly rapid. Often, the muscles become nearly useless, and patients may need the assistance of a respirator to breathe. Given its rapid and dramatic course, GBS can be one of the easier autoimmune diseases to diagnose. Fortunately, with treatment, almost all patients experience a total, or near total, recovery (taking anywhere from a few weeks to a few years).<sup>17</sup>

Aidan<sup>18</sup> was perfectly healthy until he was 10 months old. One day, after he recovered from what appeared to be a normal childhood stomach virus, his mother, Amy, found him lying listless and yellow on the bottom of his crib. After a full work-up, doctors assured Amy that this was an isolated incident of autoimmune hemolytic anemia (AHA). Instead, by the time he was 15 months old, Aidan's platelet count had dropped to nearly nothing. Given that he now had AHA and ITP, Aidan was diagnosed with Evan's syndrome (an autoimmune disease where the immune system attacks both red blood cells and platelets). By the age of 2, Aidan's health had stabilized to the point where his family was able to plan a fishing trip in remote Wisconsin. While there, Aidan became unsteady on his feet. His parents

took him to an urgent care clinic, where he was diagnosed as having complications of a previous viral illness. The family left the facility, but later that day Aidan could no longer coordinate his muscles to grab a cup. The family rushed back to the clinic, and Aidan was airlifted to the pediatric intensive care unit at St. Mary's Hospital in Duluth, Minn. An alert neurologist at St. Mary's recognized the classic symptoms of GBS. Sure enough, when Aidan's lab work came back, his proteins were elevated. Immediately, Aidan began the IVIG treatments that put him on the road to recovery.

But, GBS is not always straightforward. When Matt<sup>19</sup> woke up feeling "drunk" and "not right," doctors evaluated him for everything from stroke to brain tumors. Typically, GBS starts with weakening in the legs and symptoms progress vertically up the body. Since Matt was initially affected in the eyes and cranial nerves, no one evaluated him for GBS. With no diagnosis in sight, Matt's wife and friends combed the Internet until they discovered Miller Fisher syndrome, a rare variant of GBS. Miller Fisher matched Matt's symptoms; it became a working diagnosis and a reason to begin IVIG therapy. Almost one year later, Matt has made nearly a full recovery.<sup>20</sup> Both Matt and Aidan illustrate that persistent attention to your symptoms is critical to speed your diagnosis, so that you can get treatment and prevent complications.

## Diagnosing Guillain-Barré Syndrome (GBS)

<http://www.emedicine.com/neuro/topic598.htm>

### Physical Examination

- Progressive weakness; typically beginning in the legs and progressing up the body

### Lab Studies

- Spinal tap
- Blood work to look for elevated proteins without other markers of infection

### Procedures/Imaging Studies

- Spine MRI
- Temperature, blood pressure, heart rate, respiratory capacity, blood gases, and urine output of the patient should be monitored
- Electrodiagnostic studies

## Example of a Disease of Unknown Origin That Is Treated With IVIG

### Kawasaki disease

#### Carissa's story:

Kawasaki disease causes high fever and inflammation of the blood vessels (vasculitis) in early childhood. Children develop fever, characteristic rashes, eye complications and can suffer a heart attack or aneurysm even after they have recovered from the acute portion of the disease.<sup>21</sup> Researchers are not sure what causes Kawasaki disease; it may be caused by infection, or it may be an unusual autoimmune response to an infection or toxin.

Kawasaki disease is difficult to diagnose because there is no definitive test for it. Also, it is so rare in the ➤

<sup>17</sup> National Institute of Neurological Disorders and Stroke: NINDS Guillain Barre information page—last updated 2/13/2007: <http://www.ninds.nih.gov/disorders/gbs/gbs.htm>.

<sup>18</sup> Amy, Aidan's mom, interviewed by author on 2/19/2007.

<sup>19</sup> Interviewed by Jessica Schulman, PhD, MPH, RD, on 2/1/2007.

<sup>20</sup> For more information on Matt's amazing journey, please see "Searching for Miller Fisher" on Page 6.

<sup>21</sup> Scheinfeld N & Silverberg N, *Kawasaki Disease*, on eMedicine—last updated 12/12/2006 <http://www.emedicine.com/ped/topic1236.htm>.

## Diagnosing Kawasaki Disease

<http://www.emedicine.com/ped/topic1236.htm>

### Physical Examination

- Fever that doesn't respond to medication or antibiotics
- Rash
- Changes in the conjunctiva of the eyes
- Lip changes/swollen, bright red tongue
- Swollen limbs

### Lab Work

- Blood work to rule out other sources of infection

Note: Up to 10-45% of published cases have incomplete or atypical clinical presentations.

United States that many physicians here are not familiar with it. There are characteristic symptoms that physicians can use to diagnose the disease; however, some children may have suggestive heart complications without ever exhibiting all of the characteristic symptoms. Another diagnostic difficulty is that Kawasaki disease mimics other acute infectious diseases in young children and must be distinguished from a more clearly identified bacterial or viral infection.<sup>22</sup>

One evening, Laurisa was alone with her 5-year-old daughter, Carissa, while her husband was out of the country. In the middle of the night, Carissa woke up screaming, and her lymph nodes had swollen to the size of golf balls. She was in tremendous pain. By the next day, Laurisa could not touch her daughter without causing her to scream. Carissa ran a high fever that was not affected by medicine. Initially, her doctor thought it was strep throat.

Laurisa demanded a throat culture, even though the doctor felt it was unnecessary. Carissa began antibiotics. But, the next day, she developed a "weird" red and blotchy rash. She became listless, lethargic, and had not eaten or taken in any fluid in two days. Laurisa took her to an urgent care center where a doctor diagnosed her with scarlet fever, treated her with IV fluids and discharged her despite the fact that there was no improvement. By day seven, Carissa's tongue had turned cherry red and swelled to twice its normal size; even the whites of her eyes were red. In tears, Laurisa brought her daughter back to urgent care. The third doctor to examine Carissa was the first to do a complete examination. He took blood work and conducted a full physical. Then, he disappeared. Later, Laurisa learned that he spent three hours conducting research to discover the cause of the mysterious symptoms. When the doctor returned, it was with two other specialists who examined and photographed Carissa. Then they announced that Carissa had Kawasaki disease. Carissa was lucky. By day seven, most Kawasaki patients begin to suffer major organ complications, but, although her diagnosis was difficult and challenging, she began IVIG immediately, and is a healthy teenager today.

### In Conclusion

We have looked at a sample of the diagnoses that merit treatment with IVIG. While these diseases may seem wildly different on the surface, each illustrates a different set of circumstances that can happen when your immune system malfunctions. In

looking over the diagnostic criteria, there do appear to be some red flags—such as history of unexplained symptoms, unusual infections, unusual weakness and unusual pain. These red flags alone are just that; they are certainly not in themselves diagnostic. And, because they are so nonspecific, getting an accurate diagnosis can be difficult, especially when there is overlap between these diseases. To add to the confusion, certain defects in the immune system are linked with autoimmune disorders, and the reasons why aren't entirely clear. I saw this repeatedly with the people I interviewed. And, I was not interviewing unusual people. Twenty percent to 25 percent of people with the immune deficiency CVID develop symptoms of an abnormal autoimmune response, most frequently immune thrombocytopenic purpura (ITP) and autoimmune hemolytic anemia (AHA).<sup>23</sup>

In interviewing Amy, Kathy, Kristin, Judy, Laurisa, Matt and Valerie, I saw one clear theme: You need to push for the thorough examination that will lead to a speedy diagnosis. IVIG may not be the best treatment for every immunological disorder. In any individual case, there may be valid reason for a physician or an insurance company to choose another route. What these stories illustrate is how many different factors can prevent you from getting IVIG even when it is the best way to manage your condition. Early diagnosis is the key to prevent complications, but diagnosis alone is not enough. Once diagnosed, you need to educate yourself about your condition, your therapy options and your insurance policy to make sure that you get the safest and most effective treatment. ■

<sup>22</sup> Burns, JC, The Riddle of Kawasaki Disease, NEJM, Volume 356:659-661 February 15, 2007, Number 7.

<sup>23</sup> Carbonne J, et al, *Partial Response to Anti-CD20 Monoclonal Antibody Treatment of Severe Immune Thrombocytopenic Purpura in a Patient With Common Variable Immunodeficiency*. Annals of the New York Academy of Sciences 1051 (1), 666-671. doi:10.1196/annals.1361.111, 2005.

# MRSA

Photo by Janice Carr

## What Is It and How Can It Be Prevented?

By Jennifer Richlin, RN, MSN, PNP

January is the beginning of a new year. It is a time for resolutions, fresh starts and the Super Bowl. Many positive and exciting events are associated with January, but for me, this past January was an anniversary of a sort. This January marked one year since I was infected with an illness caused by methicillin resistant *Staphylococcus aureus* (MRSA). My experience as an MRSA patient helped me realize the importance of educating both patients and healthcare teams about MRSA and how to halt MRSA transmission. Members of the IG community need to be aware of what MRSA is, how it can be transmitted, and what the symptoms are so that they can seek appropriate medical intervention at the first sign of infection.

### What Is MRSA?

People living with a chronic illness may have heard of the common bacteria *Staphylococcus aureus* (*S. aureus*). Many people have *S. aureus* in their nose, ears or on their skin without having any adverse effects. This accumulation of bacteria is called colonization, and as many as 30 percent of the population carry *S. aureus*. Most people are unaware they harbor it, and *S. aureus* becomes a health concern for the individual only when the body becomes infected with the bacteria through a cut or wound. *S. aureus* can be the culprit for local skin infections or more complicated illnesses. The good news regarding *S. aureus* is that, in most cases, *S. aureus* responds well to antibiotic therapy.

The bad news regarding *S. aureus* is that over time and with years of treatment with antibiotic therapy, *S. aureus* has developed strains that do not respond to the treatments that had previously been effective. As a result, MRSA has become a multi-drug-resistant organism.

MRSA is spread through contact with an infected person, object or surface. Because MRSA may be carried in a person's nose or ears, in the trach tube or on the skin, without creating symptoms of illness, it's possible for a person colonized with MRSA to transmit the bacteria to another individual.

The frequency of MRSA infections is on the rise, which creates a health concern for everyone. This is especially concerning for those with chronic illness because they have increased exposure to both healthcare workers and other patients, thus increasing exposure to MRSA.

MRSA infections have been broken down into two categories: hospital acquired (HA-MRSA) and community acquired MRSA (CA-MRSA). CA-MRSA is estimated to account for 8 percent to 20 percent of new cases, and the incidence is expected to increase. CA-MRSA is defined by the Centers for Disease Control and Prevention (CDC) as occurring in a person in the outpatient area who does not have a history of MRSA and who does not have a central line or long-term catheter. ➤

### When Should I Be Concerned?

The most valuable tool in combating an infection with MRSA is early detection and adequate treatment. Contact your healthcare team at the earliest signs of concern and apprise them of any history of chronic illness. The symptoms of MRSA infections will vary with each system affected, specific to each organ and individual patient. Many MRSA infections can be mild, superficial infections of the skin, which respond well to appropriate oral antibiotics. These mild skin sores are often misdiagnosed as spider bites, as MRSA may look like a red and swollen bump that might have yellow-green drainage (pus). If the wound is not treated with an antibiotic that works against MRSA, it may expand and progress.

Again, it is important to contact your healthcare team if you have any concerns.

### Who Is at Risk for MRSA Infection?

Now that MRSA is on your radar, you need to be aware of the risk factors for infection with MRSA. An unavoidable risk factor for those with chronic illness is their increased frequency of exposure to hospitals, healthcare staff and other patients. Other risk factors include having an open cut or wound, a central line or catheter, prosthetics, chronic sinusitis, respiratory illness, dermatitis, artificial airways and compromised immune system.

### How to Prevent MRSA Transmission

Education is the key to stopping the spread of MRSA. Certain risk factors are unavoidable such as chronic illness or the need for surgery, but even individuals with risk factors can be active participants in protecting themselves and others from colonization or infection with MRSA.

It may seem obvious, but good old-fashioned hand washing is one of the most effective preventions of the transmission of MRSA. Frequent hand washing with warm water and soap is still the tried-and-true best method in infection control. If you frequent a healthcare setting or another venue where there is a lot of contact between skin and equipment, such as a gym, wash your hands frequently and for as long as it takes to sing "Happy Birthday" (singing out loud is optional).

Alcohol-based sanitizers are a great way to prevent colonization with MRSA. Send some to school with your kids and take some to work too! Do not share any personal items such as towels, razors, clothing, linens and



sports uniforms. Wash all sports uniforms in hot water and detergent, and use a hot dryer, not a clothesline, to kill the bacteria. Cover cuts, scrapes and open wounds, including surgical sites or other injuries, unless otherwise directed by your healthcare provider. Discard wound dressings in a covered trash receptacle and dispose of them promptly. Remember to always wash hands after handling any such materials.

A word for those who have indwelling catheters or central lines: Do not feel shy about asking healthcare providers to wash their hands or change gloves. It is up to patients or parents to protect themselves or their children from any potential adverse outcome in the healthcare setting, and good hand washing protects everyone from transmission of bacteria, including MRSA.

If you have been colonized or infected with MRSA in the past, discuss this fact with your healthcare team prior to any scheduled surgeries. Some orthopedic, prosthetic and other surgeries require pre-operative treatment for eradication of MRSA, confirmed by negative culture results, to prevent a recurrence or new infection at the surgical site.

### Healthcare Providers' Role in Prevention

Healthcare providers must wash their hands before and after all patient contact, and should remind others to do the same. Investigate your institution's policies and work with infectious disease teams to create MRSA screening and eradication plans. It's important to educate those in your workplace.

## What If I Have MRSA?

If despite efforts to prevent infection you contract MRSA, first and foremost, do not panic! Many MRSA infections are treated with outpatient oral antibiotics and the result is a full recovery. Remember, early detection is very important, so always discuss any concerns with your healthcare team. The challenge in combating MRSA infections is that the bacteria are resistant to the treatment that *S. aureus* responds to, so the correct diagnosis is crucial. Treatment will depend upon the severity and location of the infection along with any history of chronic illness or immune deficiency. Therapy can last just 10 days for a minor skin infection or as long as eight to 10 weeks for a bone or prosthetic infection, and usually requires oral or intravenous antibiotics.

If intravenous therapy is necessary, and you do not have a central line, discuss the placement of a PICC (peripherally inserted central catheter) line with your healthcare team. A PICC line is longer lasting than a peripheral IV, and may expedite your transition to home IV therapy if it is deemed acceptable. If you are treated in an outpatient setting, follow up with your healthcare provider in the first 24 to 48 hours to ensure that the prescribed therapy is working effectively. If any symptoms progress or do not improve, alert your healthcare team immediately. As with all antibiotic therapy, do not stop the medication until directed by your healthcare provider and do not share antibiotics with friends or family members.

## Spread the Word

Now that you are informed about how to help stop the transmission of MRSA colonization and infections, share the information with friends, family, teachers and even your healthcare providers. Become an advocate for washing hands. Working together, we can help stop the transmission of contact infections such as MRSA. ■

## Prevent the Transmission of MRSA

1. Wash your hands
2. Cover your open skin or wound
3. Do not share personal items
4. Inform your healthcare team if you have ever been colonized or infected with MRSA
5. Immediately alert your healthcare team if you suspect a skin infection
6. Stay home from work or school if you suspect you have an infection. Do not return to work or school until you have consulted your healthcare provider

## CDC Information on MRSA

The Centers for Disease Control and Prevention (CDC) is exploring a policy that would require healthcare workers to have a documented negative nasal culture for MRSA in the same way they are currently required to provide results of an annual skin test for tuberculosis. For more information about MRSA from the CDC, visit: [http://www.cdc.gov/ncidod/dhqp/ar\\_mrsa.html](http://www.cdc.gov/ncidod/dhqp/ar_mrsa.html).

In 2002, the CDC launched a website campaign to combat antibiotic resistance in the healthcare setting. For more information, visit [www.cdc.gov/drugresistance](http://www.cdc.gov/drugresistance).

---

### References:

1. Ament, Paul Pharm D., Jamshed, Namirah, MD, Horne, John, MD. Linezolid: Its role in the treatment of gram-positive drug-resistant bacterial infections. *American Family Physician*. Vol 65(4). Feb 2002.
2. Bartlett, John, MD. New clinical data on MRSA, *C. difficile*, *S. pneumoniae*, and gram-negative bacilli. 46th annual conference on Anti-microbial Agents and Chemotherapy. 2006.
3. Capriotti, T. Drug resistant Staph spreads across the US. *Dermatology Nursing*. Vol.15 (535-538). Jan 26, 2004.
4. CDC. Management of multi drug resistant organisms in health care settings. (2006). Department of Health and Human Services.
5. CDC. Vancomycin resistant Staphylococcus aureus. Fact sheet. April 2003.
6. Health Plan of Nevada. MRSA guidelines. July 2005.
7. MMWR Aug 20, 1999.48(32).707-710.
8. Ragan, P. PhD. Community Acquired MRSA infection; an update. *JAAPA*.vol19(4). April 2006.

# The Freedom to Keep Moving

By Megan Reath



*Joanne Bucholz with Popcorn*

Joanne Bucholz is a mover. As a special education teacher in one of Oregon's poorest elementary schools for 26 years, Joanne's work demanded perpetual activity, and now providing care for her aging parents, Joanne is certainly kept on her toes. Her latest move, however, is a literal one. She and Popcorn, her 22-pound feline companion, are returning to Joanne's childhood home in Oregon.

But this time last year, such mobility and freedom seemed unattainable to Joanne.

"At first I thought I was just run-down," recalls Joanne as she narrates the path to her diagnosis, which she now knows as common variable immune deficiency (CVID). At school, Joanne taught math, writing and reading. She developed Individualized Education Programs and even performed duties often reserved for occupational therapists. "I think I gave myself carpal tunnel teaching kids how to dribble a basketball," Joanne jokes. With all of this, it was no wonder that she was feeling run-down. Yet, despite its demands, Joanne loved teaching, loved the kids and loved the school.

But Joanne was having symptoms that no antibiotic effectively tackled, including respiratory complications that were causing her to lose energy. Joanne thought she was going to have to quit teaching when she was diagnosed in the 1980s with asthma. Then her immunologist diagnosed her with CVID.

Determined to maintain her career, Joanne endured debilitating monthly IVIG infusions to treat the CVID. Her protracted treatments had to be scheduled far in advance, and transportation to and from the hospital where she was treated proved burdensome.

"I would get awful reactions to the infusions," remembers Joanne, as she details the involuntary muscle contractions, dizziness and blurred vision that would immediately follow her treatments.

Craving to better understand her illness and treatment, Joanne began attending the Immune Deficiency Foundation's workshops for information on her diagnosis. She encountered an environment that was both entertaining and enlightening. The workshops introduced her to homecare, and, last spring, Joanne switched her treatment regimen from the monthly, hospital-administered IVIG to weekly subcutaneous infusions that she gives to herself at home.

Homecare has been a blessing for Joanne, who has since retired. "I'm sad that I couldn't have done this while I was working. Everything with [my homecare treatment] is portable, and, because of the low doses, I have no problem functioning the next day. There are no more hills and valleys."

Now, Joanne uses her treatment time as a relaxation period during which she enjoys a television show or book; it's a welcomed change from the hospital setting.

Although retired, Joanne remains endlessly engaged. Her parents, both 83, are beset with health complications that include Alzheimer's, diabetes and directional positional vertigo. Thanks to homecare, Joanne, whose IVIG treatment had previously tied her to a hospital, has now been able to relocate across the state where she can manage her own illness while focusing on her aging parents' needs.

These days, Joanne is able to substitute the time she used to spend recovering from treatments taking walks around her parents' 860-acre farm, where she and Popcorn enjoy surging hills, wild flowers and "ferns that go up to your neck." Still, in this verdant bliss, Joanne has to be sensitive to her respiratory system. "Popcorn likes to run through the juniper, to which I am very allergic," she laughs.

For Joanne, a change in treatment was synonymous with a changed life—for the better. "I don't have to live based on proximity to a hospital anymore. If I want to go someplace or do something, I can do it now. And that's important."

Indeed, Joanne is a mover. From stirring up her classroom to helping out her parents, she has never had much time in her schedule for sickness. With a new treatment plan and a rejuvenated spirit, Joanne embraces her newfound liberating mobility, and just keeps moving. ■

# ASK KRIS



Kris has two adult sons with chronic diseases treated with IG. Formerly a physical therapist assistant, Kris is an avid patient advocate and now works with NuFACTOR, a sponsor of IG Living. Kris is eager to find answers to your questions. Email them to [editor@igliving.com](mailto:editor@igliving.com). Your confidential information will not be used for any purpose but communicating with you about your questions.

**Andy:** I am a 43-year-old IVIG patient with common variable immune deficiency. I lead a pretty healthy life. I am considering work in developing nations, and I am trying to find out about the availability of IVIG in regions such as South and Central America and Southern Africa. Also, is it necessary for me to receive IVIG made from relatively "local" plasma donations so that I would be receiving antigens formed by people exposed to local disease agents?

**Kris:** I posed your question to a well-traveled clinical immunologist and to an immune globulin expert. They sent the following responses.

Yes, it makes sense to have IVIG made from local plasma, but I would be sure that it is produced by one of the major manufacturers. Several companies, such as CSL and BioTest, do make IVIG from local plasma, but it meets all their standards. I would be careful about locally produced IVIG, except in the more developed countries. I don't know of an IVIG made specifically in South Africa. IVIG should be available in most of the areas you mentioned, but there may be only one brand, since many countries set up contracts with only one or two manufacturers. It may be necessary to switch brands if you move from country to country. Alternatively, it should be possible to bring IVIG for personal use into the countries, although sometimes customs can be a problem. (Thanks to Richard Schiff, MD, PhD, Baxter BioScience, for these comments.)

This is from an IVIG product expert: Some countries, such as the United States, only allow plasma from donors within their own countries to be used in plasma products, while other countries may accept plasma donated from outside their country. The concern that most often arises is plasma from the United Kingdom, where the variant Creutzfeldt-Jakob disease (more commonly known as mad cow disease) was prevalent, despite the fact that it has never been shown to be transmitted by plasma-derived products. There can be a case made that plasma derived from a particular region will contain antibodies to antigens that are endemic to that area and that the IVIG products would contain some passive immunity. Most importantly, evaluate the Good Manufacturing Practices (GMP) of the manufacturer of the IVIG you choose. The standards of the fractionation plant should be equal to those employed in Europe and the United States.

**Geri:** Are there differences in IVIG products?

**Kris:** Yes, there are some differences in IG products. Although they all essentially do the same thing and all adhere to stringent FDA standards for purity and safety, you will see some of the following differences if you compare the manufacturers' product package inserts:

- Sizes of vials
- Concentration of product
- Form (liquid or powder)
- Compatibility issues (do you flush with saline, dextrose or D5/W)
- IgA content
- Sugar content
- Sodium content
- Latex stopper or non-latex stopper

Some patients also report differences in how they react to each product, especially if the patient is IgA deficient. Most physicians prefer patients to stay with one product, but ➤

availability can play a huge role in determining which product a particular patient receives for a particular infusion, regardless of any reactions a patient might have. As with all IG therapy issues, we recommend you discuss your concerns with your physician.

For a complete listing of IG products and their contents go to [http://www.nufactor.com/pages/ig\\_resources.html](http://www.nufactor.com/pages/ig_resources.html) and click on "IG chart for physicians."

**Lori:** I am looking for more information on IVIG. I now know what it is but I don't know how to get it, what the side effects can be, how will I know this is the right med for me for polymyositis? My doctor is not very open to the idea at this time, why?

**Kris:** I asked Dr. Scott Carlson, a neurologist working at the Rockwood Clinic in Spokane, Wash., to help with your question. He responded with the following:

IVIG has been shown to be very effective in dermatomyositis in controlled trials. Polymyositis is actually a fairly rare disease and usually associated with other autoimmune diseases including lupus, rheumatoid arthritis, etc. If a patient has failed steroids and Imuran, methotrexate is another oral option. IVIG would be very reasonable as an alternate that does not have serious toxicity and may provide a rapid response to someone with moderate or severe weakness that is refractory to treatment.

My only caution is to be sure the diagnosis is really polymyositis. If the patient has failed two drugs already, a re-evaluation for a dystrophy or inclusion body myositis or other alternative diagnosis might be prudent before proceeding with the expense of IVIG.

Another good link to read about the IVIG, how it is made and about the side effects is at [www.primaryimmune.org/pubs/book\\_pats/book\\_pats.htm](http://www.primaryimmune.org/pubs/book_pats/book_pats.htm). From there, click on Chapter XIV. Even though this is a site for primary immune disease, it does a good job of explaining how IVIG is made and the possible side effects.

**Shari:** I have just begun IVIG therapy. How long does it take to see results? I was diagnosed with common variable immune deficiency (CVID), and I am low in immunoglobulins. Do people see results right away?

**Kris:** I posed your questions to a good friend of mine who has spent a lifetime as a pharmacist working with primary immune deficient diseases, of which CVID is one.

The following is his response:

Every patient responds differently, and, in general, a 6-month trial period is appropriate. Many patients notice an improvement after a couple of infusions. It is important for all patients to keep a diary in which they track their infections and their severity. This is useful from a number of standpoints. First, since the improvement is generally gradual, it can demonstrate to the patient and his or her physician that the therapy is working. Second, it is helpful to have that information to provide to the insurance company when it is determining whether to continue to authorize the treatments. Finally, if the dose or frequency of IVIG infusions is changed or if the brand of IVIG is changed, it is important to be able to show the effect this change has had.

Shari, my kids have been on IG therapy for over 16 years. The treatment has allowed them to have very normal and active lives. Although IG doesn't keep them from getting infections altogether, with treatment, they see more good days, fewer infections and less severe infections. Their IG therapy also allows them to bounce back from infections easier.

As the pharmacist mentioned above, it is very important to keep a health diary. You should keep track of when an infection starts, when it ends and what medications you need to help with symptoms. When tracking the severity of infection, it is important to use some kind of quantitative scale, such as a scale of 1 to 10, 10 being the most severe. Physicians rely a great deal on what patients tell them. The more detailed the information you give your physician, the better decisions your physician can make. Remember, IVIG is not a cure, it's a treatment. The underlying immune deficiency requiring the treatment is still present. Therefore, common-sense precautions such as hand washing and avoiding unnecessary exposure to infection are always prudent.

**James:** To your knowledge, has anyone who'd previously been on IVIG been able to qualify for military service? Assuming they were using the product before enlisting for the military.

**Kris:** Although we are aware of active duty personnel receiving immune globulin therapy, they were diagnosed after going into military service.

I checked with an Army recruiter, who responded to your question as follows: Army regulations 40-51, chapter 2-30

of the Standards of Medical Fitness state that any defect resulting in an immune deficiency is a disqualification for service.

I am sorry, James, I know this is not the answer you wanted to hear. If you have any further questions, you can always talk with a recruiter to see if an exception can be made for your unique situation.

**Kelly:** Please explain IgA, IgM, IgG, etc., and tell me about SCIG infusions and insurance coverage.

**Kris:** For information about the various human antibodies, go to [www.primaryimmune.org/pubs/book\\_pats/book\\_pats.htm](http://www.primaryimmune.org/pubs/book_pats/book_pats.htm) and click on Chapter I. Pages 4 and 5 go into some detail about our antibodies and what they do. You can print this reference for free. You can also write or call the Immune Deficiency Foundation and ask for a

free copy of the manual.

As for your question about SCIG (subcutaneous immune globulin), please go to [www.igliving.com](http://www.igliving.com) and register for the IGL eZine. Then log in, click on Archive, download the February-March 2006 issue, and read the article called "On Your Own: Transitioning Teens." Also download the April-May 2006 issue, and read the article "Subcutaneous Immune Globulin Comes of Age in the United States."

Sometimes insurance companies will pay for SCIG therapy within the prescription card plan. This generally has two major advantages: First, you might have a monthly co-pay rather than a large out of pocket expense; and second, in some cases, drugs covered by prescription cards do not go against your lifetime cap. However, it is important to confirm coverage before beginning a new treatment. ■

Have questions about living comfortably with your IG therapy?  
Send them to Ask Kris at [editor@igliving.com](mailto:editor@igliving.com).

**Why did the banana  
get IVIG?**

**Because he wasn't  
peeling well!**



*Joke submitted by a 5-year-old living with common variable immune deficiency, California*

# Everyone Has a Story and This Is Kate's

By Carol K. Miletti



Sitting across the table from Kate, watching her face brighten with her radiant smile, you could see that this 18-year-old University of Minnesota student is happy to be alive, particularly given her rather rocky start to 2007. Kate, who has common variable immune deficiency (CVID), developed endocarditis (inflammation of the inside lining of the heart chambers and heart valves) and spent the end of January and early February in the hospital.

Kate's doctors think the endocarditis was caused by an infection in the port she used for administering her intravenous immune globulin (IVIg) therapy. But they did not find the infection until Kate began to have difficulty breathing and they discovered blood clots.

After settling into our conversation, Kate removed her jacket to proudly display a PICC (peripherally inserted central catheter) line in her forearm. It was delivering antibiotics three times a day for six weeks—and keeping her out of the hospital and back at school.

What was her biggest regret throughout this painful and frustrating time? "I'm just disappointed I missed a week of classes," said Kate.

This is one upbeat young lady who appears to have a good role model. Kate's mom has been her biggest ally throughout all of her health problems. She has taught Kate to live her life 15 minutes at a time. Kate knows how lucky she is to have such a

wonderful mother who understands her health issues and is always there for her.

Whenever Kate gets down, it's her mom who helps her through. She's been Kate's cheerleader since she was born. In her early years, Kate was sick most of the time. Her mom said the longest Kate went without being sick was two weeks, but it took her two and a half years to be properly diagnosed with CVID. Kate then received her first portacath for her IVIg therapy. She stayed healthy as long as she was receiving the IVIg.

By the time Kate was 6 years old, she was switched from IVIg therapy to daily doses of prophylactic antibiotics. When she was about 13, she began to get sick quite often. By age 17, she was back on IVIg and, until this past summer, she remained healthy. Then Kate was hit with GI problems, pneumonia, asthma and her current bout with endocarditis.

Now she is starting subcutaneous immune globulin (SCIG). She says she has a very low pain tolerance and is worried that this delivery system will hurt—despite flaunting her PICC line.

What does the future hold for Kate?

"I would like to get a degree in either animal science or pre-med," she said confidently. Kate has great hope that a cure for PIDD will be found in her lifetime.

In the meantime, and in spite of

her health problems, Kate has been able to maintain a 3.61 grade point average. She is also on the University of Minnesota's sailing team. She loves hanging with her friends, snowboarding and biking. And Kate's biggest challenge is shared by most serious college students: finding time to relax and stay stress-free. Kate is leading a very active life, and getting enough sleep often becomes difficult for her, although her illness demands it. When she becomes overtired, she will often pick up a bug, and it can take several weeks to recover from it.

Kate's health challenges have taught her appreciation: She is very grateful for the love and support of her family and friends. She is thankful for the support she receives from her health-care professionals and her PIDD peers. Even her professors understand and support her.

"I still feel like me. I am me, and to be honest, my CVID helps define who I am," Kate claims proudly. "It has made me appreciate life more." ■

*Note: Although ports are a successful method of IVIg administration for many patients, they remain controversial because of the risk of infection. For more information about ports, please discuss this with your physician.*

The last couple of months have been jam-packed with responsibilities: appointments, infusion center visits, resting, antibiotics, eating right, surgeries, procedures—anything and everything I can do to keep myself healthy.

Heck, if there were any way to make a living at being healthy, I'd make it my business. But, in this business there are no weekends and no days off, and the pay is living.

When I'm not feeling well, which is most of the time, I don't really think about much else but my health. I'm consumed with research, hoping I'll come across something my doctors haven't considered. So, Google has become my best friend. Although we can't share a cup of coffee,

ha I get all the feedback I need. I am comforted by information—there is almost nothing I wouldn't try to feel better.

Amidst all this self-absorption, I suddenly realized that people such as I, who are chronically ill, can become so wrapped up in our illnesses, that we completely forget about how important it is to laugh.

I had heard the expression that laughter can be a great healer, and to be honest, I couldn't remember the last time I laughed. I wondered: Does laughter really make you feel better or is it just another urban legend?

So, I found myself back on Google and I was amazed at what I found.

I learned that laughter and fun have a significant impact on health. Laughing sends more oxygen to every cell in your body, and is a great source of pain control. It distracts attention, reduces tension, changes your expectations and increases the body's production of endorphins, a natural pain killer. Wow—that's something to smile about!

According to humorist Leigh Anne Jasheway, author of "Don't Get Mad, Get Funny!" the following are major physiological and psychological benefits of laughter.

- Laughter increases the antibodies in saliva that combat upper respiratory infections. (I can use that. I think I'll start laughing now!)
- Laughter decreases serum cortisol, providing an antidote for the harmful effects of stress. (I don't think I'll ever stop laughing!!)
- Laughter causes your body to secrete an enzyme that protects the stomach from forming ulcers.
- Laughter conditions the abdominal muscles. (I wonder if I could replace my exercise routine with laughter?

Ha

- It's easier and way more fun than walking for an hour!)
- Laughter relaxes muscles throughout the body, changes one's perspective, reduces blood pressure and heart rate, has positive effects on mental function, and improves ventilation, helping reduce chronic respiratory conditions. (This is for me!)
  - Laughter is an immune booster. (Ding, ding, ding!)
  - Laughter helps your body fight infections. (Is laughter the new IVIG?!) )
  - Laughter makes you feel great! (OK, then: Ha, ha, ha, ha, ha, ha, ha!)

Some research even indicates a link between mood and the production of salivary immunoglobulin A, our first defense against bugs that enter through our respiratory tracts.

Does this mean that the more I laugh the fewer sinus infections I will get? Who knows, maybe laughter could actually save me money on Kleenex!

But how do we find the humor in all of this chronic illness stuff? When scary things are happening to me, they don't seem funny. Although, it is amazing what becomes funny in retrospect. Like when I am on prednisone, I am the most unpleasant person. A round, cranky Pillsbury Dough Girl! The last time it happened, I walked up to my family, looked at them with a seriously puffy face and asked, "Does my face look fat?"

Stunned and speechless, their look alone caused me to burst out laughing. I know it had to be absurd to hear that question coming from my red-cheeked moon face, a common and noticeable side effect of prednisone. It was funny. By laughing at it we all became more comfortable.

So, I will tell them these stories, like when I had jury duty and the security guy at the metal detectors made a huge scene because my cheeks looked suspiciously like "ripe red tomatoes."

Sure, when these things happen they are embarrassing, but later I have to admit they crack me up.

I guess laughter is good therapy, and according to my good friend, Google, there are a lot of healthcare professionals who agree.

I suspect there are a lot of patients who agree, too. Do you have a funny story to share? Send me your stories, so we can share a good laugh—[editor@igliving.com](mailto:editor@igliving.com).

Until then, put a smile on and go for it: Ha, ha, ha, ha, ha, ha, ha! ■

ha

ha

ha!

# You Know You Parent a Chronically Ill Child When...

By Dayna Fladhammer

There is something about being the parent of a child with a chronic condition that changes the way you look at things. You can be completely nonmedical and suddenly, if your child's care depends on it, you're spouting off lab values like a fourth-year medical student!

Recently, our youngest son had to be sedated for a CT scan. While going over his medical history with the nurse prior to the appointment, she asked me, "Are you a doctor or a nurse?"

"Neither, just a mom," I replied with a chuckle.

"You give such a good history, I figured you had to be one or the other," she replied.

It got me thinking about the changes in my thought process and just how much I've learned over the last couple of years, both important and trivial. Things that, five years ago, I had no idea about.

Some friends from my kids' clinic and I came up with the following list of experiences that help to define us. See how many fit you!

## You Know You Parent a Chronically Ill Child When...

- You recognize what a CBC is and can request a chem panel—and you know what you'll be getting.
- You're familiar with where the good hospital vending machines are and what's in them.
- You've explained your child's lab values to a physician.
- You not only know what all these different doctors do, but your child has more than one of them as a specialist on his or her medical team: hematologist, infectious disease doctor, gastroenterologist, endocrinologist, rheumatologist, neurologist and pulmonologist.
- You've suggested what antibiotics might work best for your child's infection.
- Not only do you know what a child life specialist is, but you have a personal one for your family and his or her beeper number is on your speed dial.
- You refer to a nurse as "our nurse."
- You know the hospital playroom hours by heart.
- You can silence the IV pump or change the volume to be infused, if necessary.
- Your child has flushed his or her own line.
- The quantity of your child's toys received as a result of a medical procedure outnumbers those received for any other reason, including holidays and birthdays.
- You have canceled plans due to a health concern more often than you've actually gone through with them.
- You've had to explain where the best place to draw your child's blood is.
- You've planned a family trip or event around a clinic day so IG levels would be higher.
- Public places are evaluated for cleanliness and number of children present, before you go in.
- You've prepped a line.
- You have suggested a test a doctor should run on your child.
- You can expertly explain the difference between SCIG and IVIG.

And, you really know you're the parent of a chronically ill child if more than a few of the above made you laugh and cry at the same time! ■

# Let's Talk!

By Shirley German Vulpe, EdD



For this column, I interviewed Matt Wright, a young father with common variable immune deficiency (CVID). Matt's 4-year-old daughter, Brianna, pictured above with Matt, also has CVID.

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

**Matt:** My diagnosis was confirmed when I was 7, and I started on intravenous gamma globulin (IVIG) when I was 12.

My mom was sick for many years. She took [intramuscular] gamma globulin shots before IVIG was approved by the Federal Drug Administration (FDA). IVIG was approved in 1982 and she started receiving it right away. My brother also had common variable immune deficiency. He had many more problems than me, like shingles. Unfortunately, he died seven years ago.

**Shirley:** It must have been difficult having three family members with chronic illnesses.

**Matt:** Sure was!

**Shirley:** Your wife, Jenny, told me that prior to your marriage you had discussed your disease with her and the possibility of your children inheriting it. How long was it after your daughter, Brianna, was born that you knew she had a primary immune deficiency disease?

**Matt:** Well, our family and her doctors all watched her very closely

from birth. Our immunologist had requested cord blood to be drawn after she was delivered, so they could start testing her levels of immunoglobulins immediately. Jenny breast-fed Brianna for six months. Shortly after she stopped breast-feeding, we had her tested. It was confirmed that she had CVID. She started on IVIG when she was 8 months old. That was rough.

**Shirley:** What kind of testing was done to diagnose Brianna?

**Matt:** I believe they were testing her various Ig levels.

**Shirley:** Have you had genetic testing?

**Matt:** Yes; however, no complete match or diagnosis was made.

**Shirley:** Are you still both receiving IVIG?

**Matt:** No, I started sub-Q last January, and Brianna started last April.

**Shirley:** Who administers Brianna's subcutaneous infusions?

**Matt:** My wife and I. Jenny puts the needles into the fatty area of Brianna's stomach and I help by taking Brianna's mind off what is happening. That usually involves some holding. At first, she cried and jumped around. Now she tolerates it pretty well and proudly announces that she didn't cry. She also tells us that she does not want an IV in her arm, but a needle in her tummy. Since she started sub-Q, her health has improved. She had a chronic

cough that went away about six weeks after she started the sub-Q. She also says that she feels better.

**Shirley:** And how about you?

**Matt:** I like [sub-Q] a lot better. I appreciate the convenience and control. I don't have to take time off work to go to a clinic and my disease no longer affects my career. In addition, my levels are higher and consistent. I don't have peaks and troughs, and I have fewer illnesses.

**Shirley:** How has dealing with all the illness affected your family?

**Matt:** I feel that it has brought us closer together. It is certainly a challenge, but we are all in this, fighting it together. Because of how frequently Brianna and I were getting our IVIG, Jenny decided to go back to school to become an RN. She really likes to help people! ■

## Genetic Testing for PIDD

For information on genetic inheritance and to determine if genetic testing is available for your primary immune deficiency disease (PIDD), please contact IG Living at [editor@igliving.com](mailto:editor@igliving.com).

The Study Targeting Immune Deficiency and its Evaluation (STRIDE) website has information about testing for PIDD at <http://www.mssm.edu/medicine/clin-immunology/stride>.

## ...Guillain-Barré Syndrome (GBS)

### Websites and Chat Rooms

1. The GBS/CIDP 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).
3. The National Institute of Neurological Disorders and Stroke has an information page about CIDP: <http://www.ninds.nih.gov/disorders/cidp/cidp.htm>

### Online Peer Support Links

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

### Books and Articles

1. "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).
2. "Bed Number Ten," by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
3. "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).
4. "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.

## ...ITP (Idiopathic Thrombocytopenic Purpura)

### Websites

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

### Online References

1. Idiopathic thrombocytopenic purpura [http://en.wikipedia.org/wiki/Idiopathic\\_thrombocytopenic\\_purpura](http://en.wikipedia.org/wiki/Idiopathic_thrombocytopenic_purpura)
2. Idiopathic Thrombocytopenic Purpura: Michael A. Silverman, MD <http://www.emedicine.com/EMERG/topic282.htm>

3. Immune Thrombocytopenia: Current Understanding and Future Research, Robert S. Mocharnuk, MD: <http://www.medscape.com/viewarticle/459249>
4. Infusion Network Systems Article: The Expanding Use of IVIG provided by ZLB Bioplasma, Inc.: <http://www.infusionsystems.net/article-ExpandingUseofIVIG.html>
5. ITP: Idiopathic Thrombocytopenic Purpura: <http://familydoctor.org/113.xml>

## ...Kawasaki Disease

### Websites

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

## ...Multiple Sclerosis (MS)

### Websites and Chat Rooms

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

### Online Peer Support Groups

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

## ...Myasthenia Gravis

### Websites and Chat Rooms

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

# Wanted to Know About...

## Online Peer Support Groups

1. MGFA's Forum: <http://health.groups.yahoo.com/group/MGnet/>.
2. Bette's Myasthenia Gravis Support: <http://health.groups.yahoo.com/group/bettesmyastheniagravisupport/>.
3. Maddy's MG Support: <http://health.groups.yahoo.com/group/maddysmgsupport/>.
4. Autoimmune Information Network Inc.: [www.aininc.org](http://www.aininc.org)  
PO Box 4121, Brick, NJ 08723, 877-246-4900, Email: [autoimmunehelp@aol.com](mailto:autoimmunehelp@aol.com).

## ...Myositis

### Websites

1. 

|  |  |
|--|--|
| <br><b>THE MYOSITIS ASSOCIATION</b> | The mission of The Myositis Association, <a href="http://www.myositis.org">www.myositis.org</a> , is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases.<br>202-887-0088 |
|--|--|
2. International Myositis Assessment and Clinical Studies Group is a coalition of healthcare providers and researchers with global approaches to improved treatments and understanding of myositis: <https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main>.
3. The Cure JM Foundation was created specifically to find a cure for Juvenile Myositis (JM), while also providing support and information for families affected by JM. <http://curejm.com>
4. Johns Hopkins Myositis Center is a new patient treatment center that brings the expertise of rheumatologists and neurologists into a single clinic for patients with inflammatory (autoimmune) and toxic (drug induced) muscle conditions: [http://www.hopkinsmedicine.org/rheumatology/clinics/myositis\\_center.html](http://www.hopkinsmedicine.org/rheumatology/clinics/myositis_center.html)

### Online Peer Support Links

1. Juvenile Myositis Family Support Network: [http://www.curejm.com/family\\_support/index.htm](http://www.curejm.com/family_support/index.htm)
2. Myositis Association Community Forum: [www.myositis.org](http://www.myositis.org)
3. Myositis Support Group UK: <http://www.myositis.org.uk/>
4. Yahoo Myositis Support Group Discussion Board: <http://health.groups.yahoo.com/group/OurMyositis/>
5. The California Myositis Symposium held in 2005 was captured on DVD. It contains information about polymyositis, dermatomyositis and inclusion body myositis, including doctors' discussions and detailed slides and explanations of muscle biopsies, skin rash, and tools used to diagnose these diseases. Other presentations offer valuable lessons in maintaining a positive attitude, exercises for physical therapy and innovative tools to aid in everyday activities. The DVD is available at no charge by sending an email to Richard Gay at [rgay@socal.rr.com](mailto:rgay@socal.rr.com).

### Books and Articles

1. "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.
2. "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.
3. "Living With Myositis," edited by Jenny Fenton, is an accessible, realistic and sympathetic guide to facts, feelings and future hopes.

4. "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.
5. "Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers," an indispensable resource for families of children with myositis and their healthcare teams, is available at [www.myositis.org](http://www.myositis.org).
6. "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.

## ...Peripheral Neuropathy (PN)

### Websites

1. 

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

### Support Groups

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

### Online Peer Support Links

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

### Books and Articles

1. "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.
2. "Medifocus Guide to Peripheral Neuropathy" is a guide to current and relevant PN research, organized into categories for easy reading.
3. "Numb Toes and Aching Soles," by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
4. "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.
5. "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. ➤

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

### Websites and Chat Rooms

- 

The Immune Deficiency Foundation (IDF), [www.primaryimmune.org](http://www.primaryimmune.org), is dedicated to improving the diagnosis and treatment of PIDD through research and education. 800-296-4433
- 

The Jeffrey Modell Foundation, [www.info4pi.org](http://www.info4pi.org), is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency. 212-819-0200
- The National Institute of Child Health and Human Development (NICHD), [www.nichd.nih.gov/](http://www.nichd.nih.gov/), is part of the National Institutes of Health. Go to the "Health Information and Media" tab on the website and do a search under "primary immunodeficiency."
- 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.
- Baxter's website, [www.immunedisease.com](http://www.immunedisease.com), offers in-depth information on immunology, PIDD and treatment with intravenous immune globulin. Click on "Europe" to see SCIG information.
- The Michigan Immunodeficiency Foundation, [www.midf.org](http://www.midf.org), seeks to improve the quality of life for Michigan residents affected by PIDD.
- 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 PIDD patients.
- To connect to a PIDD message board, go to [www.info4pi.org](http://www.info4pi.org).
- To chat with peers on IDF's Forum, go to [www.primaryimmune.org](http://www.primaryimmune.org).
- Chat with parents of children affected by primary immune deficiency at <http://health.groups.yahoo.com/group/PedPID/>.
- Chat with peers with PIDD at <http://health.groups.yahoo.com/group/PIDsupport/>.
- A group of family and friends of patients with primary immune deficiencies maintains a nonprofit network in the New England area: <http://www.nepin.org/>.

### Online Pamphlets and Education

- 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."
- "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).
- "NIAID Initiative Addresses Primary Immune Deficiency Diseases by National Institute of Allergy and Infectious Diseases" is located at <http://www3.niaid.nih.gov/news/newsreleases/2003/pirc.htm>.
- The "Immunodeficiency in Pediatrics" program or the PREP® Audio series is a new pediatrician education program that can be obtained by contacting the American Academy of Pediatrics at 866-843-2271 or visiting [www.prepaudio.org](http://www.prepaudio.org).

### Online Peer Support Links

- Chat with parents of children affected by PIDD <http://health.groups.yahoo.com/group/PedPID/>
- Chat with peers with PIDD <http://health.groups.yahoo.com/group/PIDsupport/>
- Immune Deficiency Foundation Forum [www.primaryimmune.org/forums/forum\\_intro.htm](http://www.primaryimmune.org/forums/forum_intro.htm)
- Jeffrey Modell Foundation Message Board [www.info4pi.org](http://www.info4pi.org)

### Books and Articles

- "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.

## ...Stiff-person Syndrome (SPS)

### Websites

- American Autoimmune Related Diseases Association Inc., [www.aarda.org](http://www.aarda.org), is the only national organization dedicated to addressing the problem of autoimmunity. 800-598-4668 [aarda@aarda.org](mailto:aarda@aarda.org)
- Autoimmune Information Network Inc., [www.ainc.org](http://www.ainc.org), helps patients and family cope with the disabling effects of autoimmune diseases. 732-262-0450 [autoimmunehelp@aol.com](mailto:autoimmunehelp@aol.com)
- National Association for Rare Disorders (NORD), [www.rarediseases.org](http://www.rarediseases.org), promotes awareness of rare diseases and the need for research. 800-999-6673 [orphan@rarediseases.org](mailto:orphan@rarediseases.org)
- National Institute of Neurological Disorders and Stroke (NINDS), [www.ninds.nih.gov](http://www.ninds.nih.gov), offers treatment, diagnosis and research information for rare diseases. 800-352-9424 [braininfo@ninds.nih.gov](mailto:braininfo@ninds.nih.gov)
- Diagnosed with SPS in 1994, Debra Kemery recounts her experience and offers practical information about coping with the disease at [www.stiffman.org](http://www.stiffman.org).

## ...General Resources

### Product Information

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

### Other Organizations

- 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).
- 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)

# You Ever Wanted to Know continued...

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.
6. For a pediatrician's guide to your child's health and safety, visit [www.keepkidshealthy.com](http://www.keepkidshealthy.com).
7. The National Organization for Rare Diseases, at [www.rarediseases.org](http://www.rarediseases.org), provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.
8. American Autoimmune Related Diseases Association (AARDA) [www.aarda.org](http://www.aarda.org) brings national focus to autoimmunity through research, education and patient services. 800-598-4668
9. Band-Aides and Blackboards: <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>, started by a nurse working on her dissertation, focuses on children with chronic illness.

## IG Manufacturer 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)  
CSL Behring: [www.cslbehring.com](http://www.cslbehring.com)

## Education and Disability Resources

1. Continuation of Health Coverage—Consolidated Omnibus Budget Reconciliation Act (COBRA): <http://www.dol.gov/dol/topic/health-plans/cobra.htm>
2. Social Security: [www.ssa.gov/disability/](http://www.ssa.gov/disability/)
3. California State Disability Insurance (SDI): [www.edd.ca.gov](http://www.edd.ca.gov) (Please note that each state has a different disability program.)
4. IDEA 2004 Resources: <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>  
News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities.
5. The National Disabilities Rights Network: [www.ndrn.org](http://www.ndrn.org). This website offers a search tool to find resources in your state to assist with school rights and advocacy.
6. U.S. Department of Education [www.ed.gov](http://www.ed.gov) offers a Parents section that has a subsection titled "My Child's Special Needs."
7. U.S. Department of Health and Human Services, Office of Civil Rights: <http://www.hhs.gov/ocr/504.html> spells out your rights under Section 504 of the Rehabilitation Act.
8. Wrightslaw: <http://www.wrightslaw.com/>. Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities.

9. The Americans with Disabilities Act of 1990 provides protection for people with disabilities from certain types of discrimination and requires employers to provide some accommodations of the disability. For more information, visit <http://www.usdoj.gov/crt/ada/adahom1.htm>.

## 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)

## Medical Research Studies

Check out the official website for the National Institutes of Health patient recruitment program. <http://clinicalstudies.info.nih.gov/>

The Center Watch website provides a wealth of information about clinical trials and volunteer participation. [www.centerwatch.com](http://www.centerwatch.com)

ClinicTrials.com has a registration form to request that you be notified about recruiting for future studies. [www.clinicaltrials.com](http://www.clinicaltrials.com)

WebMD has a service that matches volunteers with trials. [www.webmd.com](http://www.webmd.com)

## ...Nutrition and Food Safety Information

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

## ...Resources Just for Kids

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

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

# FFF unscrambles the uncertainty of your flu vaccine supply.



In 2006, FFF delivered 98% of MyFluVaccine orders  
on or before customers' selected delivery dates.

Secure your 2007 supply at [www.MyFluVaccine.com](http://www.MyFluVaccine.com)



You pick the dates, you pick the quantities, FFF delivers.

From FFF Enterprises, the nation's largest flu vaccine distributor | **800-843-7477** | [www.fffenterprises.com](http://www.fffenterprises.com)

IG Living  
41093 County Center Drive  
Temecula, CA 92591-9815

PRSR STD  
US POSTAGE PAID  
ESCONDIDO, CA  
PERMIT NO. 390