



# I.G. LIVING!

IMMUNE GLOBULIN COMMUNITY

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

April-May 2006

## With Loving Care

A CIDP Caregiver's  
Perspective

## SCIG

Subcutaneous Administration  
of Immune Globulin  
Comes of Age

## Hey Kids It's IG Day

A photo essay

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

12 Important Questions to Ask Before Choosing a Health Insurance Policy

# TABLE of Contents



A community service from  
FFF Enterprises and NuFACTOR Specialty  
Pharmacy Services

### Advisory Board

Wendi Chason

*The Neuropathy Association*

Fred Modell

*Co-founder of the*

*Jeffrey Modell Foundation*

Patricia A. Morrison, RPh

*NuFACTOR Specialty Pharmacy Services*

Jerry Winklestein, MD

*Immune Deficiency Foundation*

*Professor of Pediatric Medicine and*

*Pathology, Johns Hopkins*

### Publisher

Patrick M. Schmidt

### Editor

Kit-Bacon Gressitt

### Assistant Editor

Cheryl Brooks

### Creative Director

Caroline Carlson

### Art Director

Allan Bean

### Advertising Manager

Laurel McDonnell

### Graphic Designers

Allan Bean

Caroline Carlson

Kim Kinman

### Contributing Writers and Editors

Dan Bennett

Cheryl Haggard

Dayna Fladhammer

Jackie Logue

Angela Macropoulos

Carol K. Miletti

Alma Lucy Morales

Reginald Nettles, PhD

Emily J. Pulley

Jeff Siegel

Shirley German Vulpe, EdD

Copyright 2006 FFF Enterprises.

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: info@igliving.com

www.igliving.com

## Features

### With Loving Care

#### A CIDP Caregiver's Perspective

By Angela Macropoulos ..... 18

## Editorial

### We Hear You Loud and Clear!

By Kit-Bacon Gressitt ..... 3

Contributor Profiles ..... 4

## Product News

### Subcutaneous Administration

#### of Immune Globulin:

#### Is It for You?

By Dan Bennett ..... 7

### Subcutaneous Immune Globulin

#### Comes of Age

#### in the United States

By Kit-Bacon Gressitt ..... 9

### IG Treatment Tracker

By Alma Lucy Morales ..... 27

## PIDD Parenting

### Life with Your Pediatrician

By Dayna Fladhammer and  
Michael Schoenwetter, MD ..... 16

IG Living Resources ..... 22

### Hey Kids — It's IG Day

A photo essay ..... 30

## Lifestyle

### What the Test Tube

#### Doesn't Tell You

By Cheryl Haggard ..... 10

### Resilience for IG Living:

#### Planning for Change

By Reginald Nettles, PhD ..... 12

### Everyone Has a Story and

#### This Is Susan's

By Carol K. Miletti ..... 20

### Writing for Healing

By Carol K. Miletti ..... 28

### Let's Talk

By Shirley German Vulpe, EdD ..... 46

## Reimbursement News

### 12 Important Questions to

#### Ask Before Choosing a

#### Health Insurance Policy

From Patient Services Incorporated ..... 45

---

Cover: *Katie Fladhammer* featured in  
Hey Kids—It's IG Day.

### 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 x 1143, fax 951-699-9655.

U.S. subscriptions to *IG Living* are free, and readers may subscribe at [www.igliving.com](http://www.igliving.com) or by calling 800-843-7477 x 1143.

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 MSWord, in Arial font. Manuscripts should be between 600 and 1,500 words in length, with unjustified margins. 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. ©2006 FFF Enterprises Inc.

# We Hear You Loud and Clear!



In our first issue, we asked if you were out there. Your answer has been a resounding “Yes!” We heard from people who use immune globulin, from their families and caregivers, and from a lot of your wonderful friends who want to be enlightened about your world. We heard from makers of immune globulin, whose support for *IG Living* helps us reach so many of you. We heard from doctors and nurses who want to share the magazine with their patients. We heard from doctors and nurses who *are* patients. We heard from people across the United States—and outside of it—who want whatever information we can provide about successfully living with a disease treated with immune globulin.

You offered enthusiastic encouragement; you asked questions; you thanked us for wanting to help; you asked for help; you offered to help others; you shared things personal, communal, joyful and sad.

And on that solemn note, we are grateful to the many members of the PIDD community who asked that we announce in *IG Living* the death of Kathleen “Kathi” Marie Carpenter on December 27, 2005. A leading member of the community for more than 40 years, Kathi was a guiding light, a joyful soul and a source of much good humor. She is loved and missed.

Here are a few of the other messages we received:

**From California**— *Wow! You hit home! I am so glad someone is doing this. Thank you. ... Yahoooooo for you! Loved C. Haggard's story, and R. Nettles' type of article needs to keep coming!*

**From Connecticut**— *I am a patient but also a healthcare provider. Thank you for making this possible. I know I speak for many when I tell you we all appreciate it.*

**From Michigan**— *I have a son who was diagnosed with a PIDD at the age of 4. I look forward to learning all I can from your publication. Thank you for your efforts.*

**From New York**— *I looked over the magazine and really enjoyed it. I was so moved by all of the personal accounts, and I found it to be very informative. I also liked how you gave personal accounts coming from patients of all ages—it really shows the vastness of the disease.*

**From Illinois**— *Finally! When I first got CIDP I thought I was the only person in the world that had it. Thank you for doing this!*

**From Florida**— *Diagnosed with CIDP, progressive polyneuropathy and peripheral autonomic neuropathy. Receiving IVIG every 22 days and it is working! God bless you for publishing this magazine!*

All told, you seem to think that we did the right thing, starting *IG Living*, and so, we're off to our second issue. Thank you!

In this issue, you'll read about the writers who have contributed to the magazine, six of whom are patients or family members. You'll learn about subcutaneous IG (SCIG) therapy. Reginald Nettles, PhD, continues his series on resilience, while Cheryl Haggard demonstrates the fabulous sense of humor in her resilience tool kit. Carol Miletti offers some guidance on “Writing for Healing” and a profile of a physician who learned a powerful lesson when she became a patient. Shirley Vulpe, EdD, explores the challenges of obtaining health insurance, and PSI recommends 12 questions with which to challenge prospective insurers. Dayna Fladhammer recounts the benefits of building a positive relationship with her pediatrician, and *IG Living* follows Dayna and another family on their “IG Day.”

Again, we hope this magazine will provide a haven where you can kick back, surrounded by kindred souls, and laugh a little, cry a little, learn a little, and have a darn good chat about IG living. If you like the idea of *IG Living*, if you want to share in the fun, the comfort, the discussion, the “ah ha!” moments, sign up for your free subscription at [www.igliving.com](http://www.igliving.com) or fill out and mail the subscription card insert.

One last thought: We are starting a Readers Forum, so please send your ideas, your suggestions and your favorite rants to [editor@igliving.com](mailto:editor@igliving.com). ■

Kit-Bacon Gressitt, Editor

# IG Living Contributors

Allan Bean **is IG Living's art director. He contributes regularly to IG Living and designed the photo essay in this issue.**

**Quotable:** "This project was definitely a new experience for me. In this case, the goal was to tell a story, as opposed to communicating an idea or selling a product, which is what I usually do with my design work. We wanted to show the reality—to capture the look on their faces while this was happening to them. But what really struck me was how well they were able to go through it. They would watch their videos, play and laugh with the nurses, and when it was time for the IV, they'd go into "the mode"—they'd be crying, but knew it would soon be over. It was really amazing to watch that happen—to see them go through this thing that none of us looks forward to, and then quickly go back to being normal kids, laughing and playing as if nothing had happened."

Dan Bennett **is a longtime newspaperman who has covered a variety of subjects, including entertainment.**

**Quotable:** "I was surprised by how many people were affected by this, all the thousands and thousands. I was also surprised by how close-knit the community is. IG users are networking with each other, with doctors. Everyone knows everyone else, and it's a healthy sharing of ideas. The people I've met are pretty astounding. They have no choice but to carry on, and they just keep doing it."

Dayna Fladhammer **is a former junior high school English teacher. She and husband Brian have three children—Charlie, 5; Katie, 3; and Tommy, 2—who have PIDD.**

Dayna has always been interested in writing and kept a journal for many years. After her children were diagnosed, "writing was a way to get connected. It was a motivating factor in helping others." She writes at night after the children go to bed, working off notes she makes in her head when she gets an idea for a story.

**Quotable:** "I'm motivated to write because I'm writing about something that affects my daily life. When something happens to me, I need to write about it. If I go to the pediatrician and something happens, I want to write about it. My writing is a way to help others."

Cheryl Haggard **is a writer and homemaker. She and husband Mark have three children with PIDD—Calvin, 8; Caleb, 6; and Molly, 4.**

Cheryl started writing as an offshoot of speaking about the disease at luncheons and seminars. "As hard as it's been, I realized what funny things were coming out when I was speaking. So I thought I should start writing this stuff down." She says she writes when she can, working off a notebook she carries to jot down story ideas, impressions and the like. Cheryl has become serious enough about writing that she recently attended a national writers conference.

**Quotable:** "Every time we go somewhere, something funny happens. At least you have to look at it as funny and laugh at it. Otherwise, you're going to cry. That's why it has been such a great outlet for me. You can smile and laugh and see hope in what you've been through. And since someone is reading what you've written, that's the ultimate responsibility and the greatest honor."

Tom Henderson is a San Diego-based freelance photographer. He contributes regularly to IG Living, and shot the photo essay in this issue.

**Quotable:** "I don't often get a chance to shoot something like this, and I really wanted to do it justice. Here are children that other people might consider less fortunate, but they had such a positive attitude. That was really wonderful to see. Plus, they were just naturals for the project. By the very nature of the project, I couldn't give them much direction, so it was very documentary-like for me. I was the outside observer, and I had to be as unobtrusive as I could be."

Angela Macropoulos is an attorney and journalism student. Her mother, Josephine, 77, has been diagnosed with a peripheral neuropathy, and Angela is her primary caregiver.

Angela has returned to college to get a master's degree in journalism at Columbia University. She wanted to write professionally before she went to law school, but things went in a different direction. The main difference between writing legal briefs and journalism? "I have to be two separate persons—a lawyer for legal writing, and someone who gets to the point more quickly for journalism. That's not something lawyers do."

**Quotable:** "Writing about this really hasn't been hard. It's more of a labor of love. Not to write about it would have been more difficult. I've met such great characters, like the fireman [in my February-March 2006 article] who was in 9-11. That's why I can write—when I'm really inspired. I feel very passionate about this, and there are so many different contexts to write about. For instance, there's so much more that needs to be done, and people need to know that. It's one of those things, a disease that doesn't have a spokesperson to raise awareness."

Carol K. Milette is a self-employed salesperson. She was diagnosed with a primary immune deficiency disease almost four years ago.

When Carol was in school, her professors told her she should write. She has since taken classes about dealing with chronic illness through writing. "It gets everything off my chest. I have a sense that when I write and share my feelings, I can help other people with the same things. I've always written whenever something major in my life happens—my father dying, my divorce. I just sit down and start writing. I've found that if you write from the heart, you won't get stumped."

**Quotable:** "One of the things that has surprised me is how easy it is to get through security at an airport. I have a lunch bag I carry with my needles, and they just take a look at it and wave it through. I guess they're used to seeing diabetics."

Alma Lucy Morales is a healthcare company employee. She moved from public relations to healthcare in August 2004, and appreciates the idea of patient advocacy. "It's been quite an interesting transition, from writing about condominium developments to healthcare."

**Quotable:** "All of this was very new to me. I have never really been able to put a face on these kinds of issues before—people and their health. It makes you want to make a difference. I wasn't emotionally in touch with what I did before. Now, I'm more passionate about what I do. Looking out for patients is our No. 1 goal. And to write something, to see how it comes across, to hear from people about it, that's really an insight into the way the system works." ➤

Reginald Nettles, PhD, is a psychologist. He contracted polio as a child and has since been diagnosed with gamma globulin anemia. His medical history has inspired him to help others facing similar situations.

Writing is part of his professional research into how the chronically ill can lead fulfilling lives despite their illnesses. "How do people survive? What do they do to cope? I'm looking for ways to connect and to identify with other patient populations to answer those questions. I'm kind of learning as I go. It's just natural for me to want to learn more."

**Quotable:** "I remember learning that [my diagnosis] was something the medical profession didn't know anything about. And the stories I've heard as I have researched this have been heartbreaking. For instance, why some people—and I knew a woman who worked for my cleaning company that fit this—aren't diagnosed. Why does the healthcare system fail them? Is it because they don't have insurance or that their doctors aren't aware? But there is always the potential for resilience, which is something the psychological profession is starting to pay more attention to. They are beginning to recognize that ordinary people cope with extraordinary events in their own ways. Some of these are noteworthy enough to share with others."

Emily Pulley is a healthcare company employee, and has worked in the industry for the past several years.

**Quotable:** "The one thing that has always struck me when I write about this is everyone's attitudes. They have this serious disease, and they say, 'It's not a big deal, whatever,' and then I start to think, could I have done that myself if I were in their place? They're just so amazing, the way they accept what has happened. That's the one big difference about working here. It's not just a large corporation. It's a place where you deal with people's personal lives and struggles."

Jeff Siegel is a freelance writer. He contributes regularly to *IG Living*, and has written six books, contributed to four more, and written a video, in addition to magazine work for publications such as *Gourmet*, *Sports Illustrated*, and *Southwest Spirit*.

**Quotable:** "It's actually a pleasure to do some work for a company that shows that not all [businesses] only care about money, that there are drug companies where people and patients and families are actually part of the equation. When I talked to many of the people in this issue, they had nice things to say about the company. When's the last time you heard anyone say that about the pharmaceutical business?"

Shirley German Vulpe, EdD, is a retired occupational therapist. She was diagnosed with a gamma globulin deficiency nine years ago and had to retire. Since then, she has used subcutaneous administration for her treatment, working with several doctors and researchers on this cutting-edge approach. "What's happened has been a miracle."

Shirley has a researcher's perspective on PIDD, "but I'm also doing it for myself as well as from the research orientation. So I've gathered up a lot of information that I have volunteered to share after attending the [NICE] conference in the fall."

**Quotable:** "You have to learn everything there is about your illness, or at least that's what I believe. Otherwise, how are you going to know how to put everything together?"

# Subcutaneous Administration of Immune Globulin Is It for You?

By Dan Bennett

**L**iving in a house made of steel and concrete seems like a good way to fend off intruders.

When intruders are in your own body, though, you need all the reinforcements you can get.

Marilyn McVicker knows a lifetime of intrusion and illness. After a sickly childhood, McVicker was diagnosed at age 17 with IgA deficiency, asthma, allergies, chronic rhinitis, bronchitis and pneumonia. In her 20s, she developed malar rash, low-grade fevers and joint edema, in conjunction with pneumonia and bronchitis, and had positive autoantibody tests.

"I was also diagnosed with mixed connective tissue disease," McVicker said. "By my 30s I had to leave my profession and go on disability, because I was sick a majority of the time. I was ill from exposures to people, crowds, sunlight, chemicals and irritants, foods and medications. During this time, my blood levels were checked, and I was found to have continued IgA deficiency, with two IgG subclass deficiencies, a C-3 deficiency and neutropenia. I was having increasing difficulty with illnesses, infections and sensitivities to chemicals, fragrances and irritants. I left the city and relocated to a cleaner environment."

It was in North Carolina that McVicker built her house of concrete

and steel to help protect her from her allergies. Illness continued, though, until a doctor at last figured out that McVicker needed injections of an intramuscular immune globulin. Then, a year ago, McVicker began intravenous (IV) infusion of immune globulin, but she had problems with vein access, distant hospital visits and other factors.

*"Subcutaneous administration went beyond the disappearance of adverse side effects.*

*It was freedom for me.*

*It was treatment at home.*

*It was a total improvement in quality of life."*

"My treatment was often delayed because of unavailability of the specific product prescribed by my physician," she said. "I was having reactions following hospital visits, because of my susceptibility to infections, and [reactions to] chemical fragrances and disinfectants. The nursing staff was having increasing difficulty finding venous access. It was taking close to an hour to get an IV started, with new sites being used, such as the bony arch of my foot. Needless to say, it was not pleasant."

In September 2005, McVicker began taking her dosage subcutaneously—or the popular shorthand "SubQ"—one of an increasing number of IG consumers to do so.

An off-label use for most brands of immune globulin (ZLB Behring began marketing the first U.S.-licensed subcutaneous product in January), the subcutaneous method involves immune globulin self-administered under the skin. It is sometimes recommended when vein access is consistently difficult or adverse side effects from IV administration occur. This method has long been approved in Europe and enjoys popularity there.

"Using the subcutaneous method has changed my life, and I'm only getting 3 grams," McVicker said. "It's remarkable that subcutaneous infusions have solved all of the problems I was having with IVIG. I no longer have to travel backcountry roads, and I am able to infuse at home, alone, with neighbors as backup for me. I no longer have to worry about encountering flu epidemics or other pathogens at the hospital. And most pleasant of all, I do not have to sit there while someone torturously tries to fish around for about an hour to find a vein."

McVicker has slowly increased her dosage. "I am currently receiving 3 grams a week or 12 grams a month— more than double what I could tolerate intravenously," she ➤



said. "I still have not reached therapeutic blood levels, but I am definitely improving."

Neil Ross can relate to such improvements. Ross was also having trouble adjusting to IVIG infusions, experiencing severe stomach reactions, chills, fever and aches and pains. Two years ago, Ross began looking for a change.

"I went on a search," said the 50-year-old sales representative. "I told my doctor, 'Let's not do this anymore.' I started doing research and found that subcutaneous was increasingly popular in Europe. Of course, it was extremely off-label here, and the thinking was that you almost had to be in the hospital before a doctor would consider it. But I was able to try it, and the results were just what I needed."

Changing to subcutaneous administration went beyond the disappearance of adverse side effects, Ross said. "It was freedom for me. It was treatment at home. It was a total improvement in quality of life. I found just the level I needed in three months."

Ross now not only feels better himself, he helps others in similar situations, as a sales representative for a homecare services company and as a volunteer for an immune deficiency advocacy group.

"There are only 50,000 people diagnosed [with primary immune deficiency disease], and I know what those people are going through," Ross said. "I've had a lifetime of illness, and I know what it's like to catch something every time you go out of the house. It makes me feel better just knowing I'm helping other people out there."

Dr. David Lewis, a professor in the department of immunology and transplant biology at Stanford School of Medicine, and an attending physician at Packard Children's Hospital in Palo Alto, Calif., sees subcutaneous administration as a leading method in the future.

"I routinely offer SubQ as an option now," said Lewis, who had a dozen or so patients using the method last year. "If the patient has never been on gamma globulin, I start them on IV so they can get up to a therapeutic

level right away. After a couple of doses, we make the change [to SubQ]." Lewis says there are several issues

involved in the choice between IVIG and SubQ. "In very young kids, there are sometimes some technical issues," he said. "Children and adults are open to the idea, while younger adults sometimes prefer to get the treatment over right away."

Lewis has seen some success stories with the SubQ method. "Some results have been remarkable," he said. "I have a patient who was having a terrible reaction to IVIG, but we were able to get her back on therapy with SubQ. The big advantage of SubQ is there is very little decrease in terms of safety, while avoiding the negative side effects of other methods."

### **Long-term costs are another factor.**

"I would not be surprised if SubQ became the dominant form of administration, not only because of the physical benefits, but also because it's more cost-effective," Lewis said. "The word of mouth about SubQ among patients and families will give the method more power. I'm optimistic about that, and I think most clinicians are now quite comfortable with the method."

Patients such as Marilyn McVicker will likely be among those spreading the word. "My staph skin infections have lessened, and my overall health, energy and wellness have improved to the point that, for the first time, my doctor is encouraging me to have guests," McVicker said, just before Christmas 2005. "My daughter and my little granddaughter will be visiting me for the holidays, and I am thrilled. I have two grandchildren who I haven't even met yet, and I am looking forward to meeting them, as we space out our visits, and weave our way carefully into a life that seems hopeful, a life that will include family contact, improved health and a new quality." ■

---

*In the June-July 2006 issue of IG Living, we will explore immune globulin administration via a port.*

# Subcutaneous Immune Globulin Comes of Age in the United States

By Kit-Bacon Gressitt

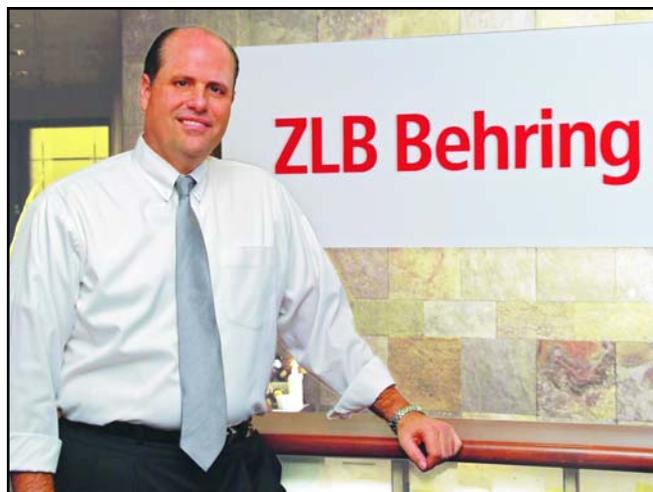
ZLB Behring, an immune globulin manufacturer with U.S. headquarters in Pennsylvania, announced in January that the company received FDA approval for Vivaglobin®, the nation's first licensed subcutaneous immune globulin (SCIG or SubQ) for patients with primary immune deficiencies. This is exciting news for U.S. patients, physicians and insurers who have been awaiting a U.S.-licensed subcutaneous product.

The method of administering IG subcutaneously, or under the skin, is gaining increasing attention from U.S. patients and physicians, having been well established in Europe for more than 10 years (see this issue's article "Subcutaneous Administration of Immune Globulin: Is It for You?" Page 7).

With the FDA approval of Vivaglobin, U.S. patients now have an additional treatment option for the delivery of IG, an option that may prove beneficial to those experiencing problems with intravenous (IV) infusions.

Paul Perreault, ZLB's executive vice president for worldwide commercial operations, described the new product's benefits. "We're all very excited about bringing Vivaglobin to the U.S. primary immunodeficient patient community," Perreault said. "Vivaglobin avoids the need for supervised IV infusions, providing an important alternative for those patients who have poor venous access or IV side effects."

Perreault encourages patients to discuss SCIG with their doctors. "Physicians play a big role in this," he explained.



Paul Perreault, ZLB executive vice president for worldwide commercial operations

"Patients should be discussing this with their physicians to make sure they are good candidates for Vivaglobin. It's an important advance in patient care, and, over time, SubQ will become more popular with patients for whom this is the right product—but that will take time and education for both patients and physicians so they understand the benefits."

ZLB Behring invested five years in bringing Vivaglobin to the United States, after successfully marketing it in Europe. "It has been a fairly long process, mainly because of the consolidation within the plasma therapeutics industry," Perreault said. "Immune globulin is not an easy product to manufacture, but Vivaglobin represents an innovation in IG therapy, and I think there is more to come from ZLB in the delivery of immune globulin to U.S. patients."

For more information about SCIG, visit [www.vivaglobin.com](http://www.vivaglobin.com), [www.primaryimmune.org](http://www.primaryimmune.org), [www.jmworld.com](http://www.jmworld.com) and [www.nufactor.com](http://www.nufactor.com). ■



# What the Test Tube Doesn't Tell You

By Cheryl Haggard

**G**etting a diagnosis for the perpetual green slime falling out of my kids' heads was as exasperating as getting that little piece of shell fragment out of Sunday morning's scrambled eggs: I knew it was there, but putting my chubby finger on it was nearly impossible. Yet, however frustrating this journey we called "finding the DX" became, euphoric epiphanies *did* erupt, and I'd like to share three of them ...

## Take Me! Take Me!

The crazy world of lab work has convinced me that my kids' body fluids have been to more exciting places than I have. When test results come back, jealousy burns within, as I see where their precious blood has been gallivanting. I ponder: Boy, a trip back East sounds nice, especially in the fall when the leaves are turning those gorgeous shades of burnt umber and orange sherbet. Or how about a trip to Northern California, where no wine is poured before its time?

Nothing was more infuriating than discovering a temperature- and time-sensitive blood test was botched while being airlifted to a hospital lab two states away—a state known for its world-class skiing! Next time, the lab is sending all of us with the test tubes, and we'll turn our blood work into a family vacation.

Our immunologist was dumbfounded by the results of some of the kids' globe-trotting blood, so he asked our offspring to provide saliva samples to check for antibodies. "We'll have the kids chew on this piece of gauze, and I will extract their saliva into this tube," he said.

"Are you serious?" I asked carefully.

*A spit-spit here and a spit-spit there was going to solve the mystery of the mint green runny noses?* I pondered.

"I want to get a sample from you and your husband as well," my confident doctor declared.

"Fine," I quipped, "but I have one question."

"What's that?" he asked.

"To what part of the country is our spit going? We'll make a second honeymoon out of it," I retorted.

## Floors Are Our Friends

I appreciate physician waiting rooms that are chock-full of toys to entertain my kids. A family favorite, and the king of germ-spreading, is the wooden ball thingy that begs every infectious 3-year-old to take the colorful beads on the roller-coaster ride of their lives. Straining in my waiting-room chair, I debate with myself: *Do I let them play with the bacteria balls while I read the Parenting magazine article about hand washing or do I make them practice writing "Froliche Geburtstag" for Grandma's birthday card?* The call is hard because I know needle pokes are in their near future and they are having such a good time just being kids.

The examination room is not quite as exciting as the celestial space we have just shared with 10 other contaminated people. It is in this room where critical conversations take place on behalf of my undiagnosed children. It is also the place where the kids have learned to entertain themselves, as toys are now extinct. At this time, I often pray for Super Nanny to pop out of the drawer that hides the ocean blue plastic bed liners that are for my personal use after the doctor says, "Well, the kids look pretty good today."

On one particular office visit, I prepare myself for a one-way trip to "Anywhere But Here," as our pediatrician is trying to explain why Caleb needs to start immune globulin infusions. As I'm blubbering on about this gamma globulin stuff, the doctor begins to giggle.

"What's so funny?" I ask, taken aback.

"Look!" he responds, gesturing toward the floor.



My son, who had so valiantly fought for every breath the night before, is prostrate in a face-to-floor battle for the life of a misguided cockroach.

"Caleb," I bark at my sickly child. "Get off of the floor!"

Our doctor, a father of three boys himself, shushes me as if I were his 3-year-old, but everything within me screams, "Quit blowing that disgusting creature all over this germ-infested floor!"

"Don't, Mom," our pediatrician scolds me. "He's got a job to do!"

As the roach quietly slips under the finish line that is the heavy examination room door, Caleb's entertainment is finished, and so is my conversation with the good doctor. He hands me the orders to start Caleb's infusions, and I come to the conclusion that we still have to live, even though we might feel like dying.

### But Can She Say Heparin Lock?

I've had a love-hate relationship with some of my buddies whose kids can easily romp in the fast-food restaurant's play place without getting a rousing round of rotavirus. If their kids ever threw up, these parents were the type to call the county's infectious disease control.

Me? Well, I'd just be happy if my kids made it to the toilet before the fifth heave. I've had to learn the hard way not to compare my chronically ill kids to their playmates.

Recently a friend brought her 1-year-old infant over to play with my slightly older daughter, Molly. Because Molly

spent her first year of life attached to an IV pole and under the care of an ENT sucking gunk out of her ears, she was at a slight disadvantage in her phonics lessons.

After a few rounds of color-coded flash cards with her perfectly-pink daughter, my friend asked me in amazement, "Did she just say what I think she said?"

"Huh?" I smartly replied.

"My daughter just said 'yellow' when I showed her the flash card! She said 'yellow,' I just know it!" my friend exclaimed.

The proud mother of the next Rhodes scholar blithered on, "She said 'yellow'! I heard her! Oh, good girl! You said 'yellow'! You are such a smart young lady! Good girl!"

The baby cooed at her gushing mother, and all I could do was stuff a cookie in my mouth to prevent the good belly laugh I felt welling up inside me.

I didn't have the heart to tell her that Molly's first word was "pneumococcus."



Yes, we are still grasping at the shells in the slimy scrambled eggs, and this diagnosis stuff has been no walk in the park, but I'm hard-pressed to dismiss the silliness that has occurred as a result of this journey. Just yesterday, while we were waiting for a CT of the kids' sinuses, our son asked an ambiguously dressed patient sitting next to us if s/he were a boy or a girl.

Nope, I wouldn't trade this for anything. ■

# Resilience for IG Living

## Planning for Change

By Reginald Nettles, PhD

*This is the second article in a series on resilience, the capacity to bounce back from adversity, trauma or stress, including the stressors associated with chronic disease or frequent acute illness. The ability to make realistic plans and take steps to carry them out is a key factor in developing resilience.\**

### The Resolve to Change

If you are like many people, you made a New Year's resolution (or two?) in December or January. Most people who make resolutions intend to do something very worthwhile and meaningful in the coming year. If you have a chronic illness requiring regular and frequent immune globulin infusions or if you are a parent or other caregiver, chances are your New Year's resolution had something to do with a goal to improve your health or reduce the stress associated with chronic illness.

Although many people succeed in keeping their New Year's resolutions, others are unsuccessful, giving up on their resolutions before the end of January or even forgetting what they were. Post-holiday depression is another factor related to failure to reach new goals established in the heat of holiday celebrations. People often tend to be fatigued after the holidays, despite efforts to celebrate in moderation. It can be difficult enough to get back to old routines and even more difficult to start off the new year with new ones. People with chronic illnesses may find the holidays and their aftermath especially difficult because of the energy demands of preparation for and enjoyment of the holiday season. If your mood drops after the holidays, it may be easy to turn to the very comforts your resolutions beg you to avoid, thus defeating your resolve.

This is unfortunate because achieving what we resolve to do may enhance our capacity to live well with chronic illness, but, with a good plan, you can get back on a path to success.

Now that spring is upon us, do you remember your resolutions for 2006? If you do remember your commit-

ment, you are in good shape for picking up the process wherever it may be at this point and continuing on toward success. Much of what we resolve to change at year's end involves habitual behaviors—we do tend to be creatures of habit, and habits by their very nature are difficult to change. So, understanding what we need to change to manage our lives with greater resilience is an important first step. The next step is understanding how behavior change takes place, so that we can match our resolve with success.

While it is very easy to allow bad habits to become chronic when faced with the emotional toll of chronic illness, healthy behaviors are important areas of focus for people with chronic illnesses. Good health practices for people with primary immune deficiency diseases and related disorders are similar to those recommended for most people: eat a healthy diet, maintain normal weight, get plenty

of sleep, exercise regularly and drink plenty of water. This general prescription will vary with different conditions and during periods of acute illness. For instance, some people will need to take care to keep their weight up to normal, while others may have to work harder at keeping their weight down to normal. During periods of illness, it can be difficult—and may not be advisable—to maintain normal activity levels. Ideally, however, good health practices become habitual behaviors.

*Resolutions are  
often made  
as a first step  
toward change.*

### Planning for Change

Chronic illness can affect all areas of life, including personal relationships, work roles, physical activity levels and self-confidence. As a result of current advances in



immune globulin therapies and related treatments, people with primary immune deficiency diseases, peripheral neuropathies and other chronic illnesses are increasingly able to live relatively normal lives, thus making planning for a productive future realistic. Taking the presence of a chronic illness into account in education, career and retirement planning, based on prior health experience, can reduce some of the stress that can occur if goals become unreachable. The ability to make plans and carry them out—often in incremental steps—can aid in maintaining confidence, a positive view of oneself and resilience, that ability to bounce back when adversity hits.

Resolutions are often made as a first step toward change. If we think of change as a process rather than an event, the likelihood of success is much greater. According to the Transtheoretical Model of Change, successful change processes involve five stages: precontemplation, contemplation, preparation, action and maintenance. Termination may be seen as a sixth stage, signaling long-term success and exit from the change process per se.

In precontemplation the person has not given serious consideration to making the change and may use rationalization to avoid thinking about it. The contemplator has heard enough about, for instance, the links between dehydration and difficult infusions to be consciously aware of the need to drink more water, especially in the days leading up to the next treatment. The action stage is

obviously most important; this is what we resolve to do. But successful change processes require preparation before moving into action. It can be too tempting to leap from contemplation (we agree this would be a good change to make) directly into action. When this happens we resolve to, for instance, exercise more regularly, without developing a plan for doing so. Then we hit post-holiday blues, begin to feel like slugs, and by the end of January we have

not yet developed an exercise plan that works for us, and very little has changed in meeting our exercise needs. We may then feel we have failed and give up trying.

Readiness to change—how prepared a person is to enter the action phase—has been found to be “the single best predictor of New Year’s resolution success.” In preparation, a person has decided that the pros of making the change outweigh the cons, and he or she has begun to identify the specific steps needed to make the change.

But change has to be manageable. This means structuring your personal environment to facilitate reaching your goal. Getting rid of all of your cigarettes and ashtrays, placing your workout routine in your daily calendar or giving away all of those wonderful chocolates you collected over the holidays are all examples of preparation. Having a special quart-sized water bottle to be refilled daily, for instance, can be an effective environmental cue to increase water consumption to the level your health-care provider recommends.

Once into the action stage of change, it is important ➤

*Thinking of the stages  
of change as a  
“spiral of change”  
is more consistent with  
how successful change  
actually happens.*

to set up systems to reward new behaviors and avoid high-risk situations. You should also expect to be in “action” for a minimum of three to six months before feeling assured of success. It may be heartening to know that research participants who committed to behavior change by making a resolution were 10 times more likely to succeed than those who were not ready to put plans into action. Careful planning and realistic thinking are important ingredients in successful change efforts.

Change, according to the Transtheoretical Model, includes periods of relapse to earlier stages in the change process. “Relapse” can be experienced as failure if you are not careful. Instead, try to sort out why the slip-up happened, use it as a tool for learning and self-understanding, and rebuild your action plans with this new knowledge in mind. Thinking of the stages of change as a “spiral of change” is more consistent with how successful change actually happens. People do not move toward achieving new goals in a linear fashion. Most often, people spiral through the stages, periodically revisiting earlier stages. Relapse in this model is seen more as an instance of “recycling.” Therefore it is important to avoid feeling discouraged by slips and backsliding after successful change has occurred. Periods of high stress and social pressure may contribute to reverting to old habits, which may undermine our change efforts unless we recycle back into our personal contemplation-preparation-action process and continue forward motion.

Social support can also be important in maintaining change. Enlisting the help of family members and caregivers for support through the action phase and beyond can be enormously helpful in continuing toward successful achievement of your new goals. If exercise is an area of necessary change for you, how about finding a walking

buddy who will join you in your daily exercise routine?

Family, friends, and caregivers have a special role in assisting the person with chronic illness to make changes to enhance resilience. People who are engaged in changing their behaviors or achieving new goals benefit most from support from others while in the contemplation, preparation and action stages. Warmth, empathy and positive reactions to successful efforts are most helpful.

Too often, though, people trying to help will push a person who needs to change in ways that are counterproductive. Caregivers can become frustrated when the person with chronic illness has not yet begun to think of changing or moving forward. Efforts to help can turn to nagging, which can only generate defensiveness and work against successful change in the long run. On the other hand, consciousness-raising can be helpful, and providing new resources may excite the person’s interest in changing.

Qualified professionals, including psychotherapists and professional life coaches, can work with individuals or groups in developing and maintaining life change strategies designed to enhance resilience. Support groups—virtual as well as face-to-face—can be quite helpful for some. In addition, message boards and the variety of online communities can be helpful in providing useful peer support for people with chronic illnesses.

The National Organization for Rare Diseases ([www.rarediseases.org](http://www.rarediseases.org)) provides links to numerous other organizations, some of which have disease-specific support groups and virtual communities that are available for patients and caregivers. Supportive relationships are an important part of your resilience tool kit. Seeking support from a variety of such relationships can increase your resilience for living with chronic illness.

*When you are ready  
to move forward,  
set goals broken down  
into manageable steps  
that you feel you  
can achieve ...*



## Implementing Your Plan

If you still remember your 2006 New Year's resolution, sincere congratulations! This information may help you to examine where you are in your process of change and make improvements where needed. For those of you who have not been so successful, you may want to go back to the contemplation stage briefly to examine the pros and cons of the change you wish to make. If you still feel inclined to pursue your resolution, start the preparation stage of change, and visualize the action steps you will need to implement to move toward change. Call it a mid-year correction, and keep in mind that the planning stage takes time. When you are ready to move forward, set goals broken down into manageable steps that you feel you can achieve by midsummer. After a few months of forward motion, you will be sure to be on the road to making your successful New Year's resolution for even greater resilience in 2007! 🍀

---

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

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

## Transtheoretical Model of Change STAGES OF CHANGE

1. **Precontemplation** describes the stage where one is not considering changing a particular behavior. In staging physical activity, this person would be inactive and not considering becoming active anytime in the foreseeable future.
2. An individual enters the stage of **Contemplation** when he or she becomes aware of a desire to change a particular behavior. This stage likely describes a number of sedentary citizens in the United States who think about being active, but lack sufficient commitment to change their behavior.
3. The **Preparation** stage of the model indicates not only a desire to change, but also evidence of commitment to make that change in the near future, traditionally within the next 30 days. Someone in the Preparation stage of change for regular, moderate physical activity might seek information describing regular activity, make a few phone calls pricing local gyms or rally verbal support from friends and colleagues for a lunchtime activity plan.
4. The **Action** stage is where the change in the criterion behavior actually occurs. Progressing through this stage may include intense effort to modify behavior itself as well as the environment in which the behavior occurs, and is expected to endure for about six months. When considering physical activity, Action may mean changing routines, reallocating time, and developing strategies to cope with the many environmental barriers to engaging in physical activity.
5. **Maintenance**, the fifth stage, consists of ongoing change of the target behavior. However, individuals are often faced with preventing relapse back to an earlier stage. The seasonal climate changes in many parts of the United States provide a good example of how relapse may be difficult to prevent during Maintenance. As the days grow shorter and colder, maintaining levels of activity may pose a challenge.

**Source:** <http://www.umbc.edu/psyc/habits/TTmodel.html>

# Life with Your Pediatrician

By Dayna Fladhammer

Michael Shoenwetter, MD

There are few things in this world worse than sitting in your pediatrician's office with a chronically ill child, worried about his or her health and feeling as though no one cares. My husband and I have worked very hard with our pediatrician and his staff to build a strong relationship for the sake of our children. We consider Dr. Michael Schoenwetter—Dr. Mike, to the kids—and his office our medical home base, a place where we feel safe.

Unfortunately, building a good relationship with the pediatrician can sometimes be a difficult undertaking. However, it's an important part of managing a child's primary immune deficiency disease, so you must make the effort. Your pediatrician is the main contact point for all the specialists you'll need, and he or she will be the doctor who sees your child most often. We've learned some lessons from our relationship with Dr. Mike that may help you establish a great working relationship with your pediatrician.

**Don't underestimate the value of connecting.** Both you and your child need to connect with the pediatrician. Let's face it, there are people you connect with and people you don't. If you and your child's pediatrician don't click, the likelihood of its being a positive relationship is pretty slim. For your children, it



*Dr. Mike hugs Tommy Fladhammer while listening to Charlie's tale.*

might be something as simple as how the doctor approaches them that makes them feel safe. Kate, our 3-year-old, will often sit in Dr. Mike's lap and tell him about what's new in her life first. She needs to reconnect with him before she's willing to let him examine her. Dr. Mike always gives her the time to get comfortable first, and that's invaluable, because she's learning to trust her doctor, which will help her with the multitude of exams she faces over her lifetime. While it's important to give every relationship a chance, you do not need to stay with a doctor with whom you or your children don't connect.

## **Communication is the key to a parent-pediatrician relationship.**

As in all relationships, very little is possible without communication. Dr. Mike feels the key to selecting a good pediatrician is finding one who listens to you and to whom you will listen. A pediatrician skilled at communication will have most of the following qualities: the ability to say "I don't know" and refer you to specialists—and communicate with them; a willingness to learn the unique nature of your child's case; the ability to answer your questions and translate medical terms into language you can understand.

Communication is a two-way street, so, on the flip side, parents are responsible for really listening to their child's pediatrician and reporting accurate histories. Unless you report your concerns, your doctor can't help. Don't forget humor, either. A little humor can often break the ice, and it will help get you and the doctor through even the most difficult situations. While pediatricians are not therapists, they often can offer insight on issues that chronic illness can add to a family. Don't hesitate to discuss emotional issues, especially when they relate to your child's health condition. Tell your doctor when you are frustrated and why. Knowing the entire picture will help your doctor treat the whole child, not just his or her physical health.

**Engage the staff when possible.**

When our kids see Dr. Mike, we often spend an hour or more in the office, approximately 20 minutes with him and the other 40 with his staff members. It can be helpful to let the office staff know your child's condition, and take the time to get to know the nurses, their names, and even a little about them personally. For instance, Anna, a nurse in Dr. Mike's office, is a wonderful cook, and when I run across a good recipe, I pass it along to her. Now, many times when we've walked into the office, the staff has warned us that they've seen a lot of cases of a specific illness that day, and that

we should not sit in the waiting room because of infection risks. The relationships we've been able to develop with the staff have helped us to feel more connected to the entire office and, consequently, improve our children's care.

**Playing by the rules will help your relationship.** The doctors and staff will know your family better than others because of the amount of time you'll spend there, but resist the temptation to abuse that intimacy. Although we know our pediatric group well, we never try to call in through the back number or on the emergency line for non-emergency calls. We pay the co-pay at the time of service. And, when Dr. Mike has called us from his cell phone, we've never used that number to call him. We remain polite and show our appreciation, even when we feel frustrated or overwhelmed, and we require the same of the children. It is also important to be flexible. Your doctor's office will often be able to accommodate you, so when you have the opportunity to be flexible for them, take it. They respect us more when we respect them and their rules.

**Your pediatrician should be accessible and available.** Different practices function better with different types of communication. Find the way that works for you and your pediatrician. It might be email, beeper or phone messages. While it's important

that there is a way for you to reach your doctor, that he or she returns calls and has time for your child's needs, it's also important not to abuse that time. Doctors are busy, and inundating them with requests can make life difficult for them.

**Trust is an important part of the patient-doctor relationship.**

You must be able to trust that your child's doctor has your child's best interest at heart, and your doctor must be able to trust that you will always be honest. It is this trust that makes your child's pediatrician a safety net, a home base between specialists.

The parent-pediatrician relationship is like any other relationship in your life: It is important to nurture it. The right doctor can have a lifelong role in your child's life, and so can the wrong one. Eventually, children with an immune deficiency will grow up and be responsible for their own healthcare. Now is the best time to teach them how to develop long-lasting, working relationships with their healthcare providers. ■

---

*Dayna Fladhammer is a parent of three children with primary immune deficiency disease. Dayna can be reached at editor@igliving.com. Dr. Mike Schoenwetter, a native Californian, attended college at UCLA, graduated from UC Irvine School of Medicine and completed his pediatric training at UCLA. His practice is located in Valencia, Calif.*

# With Loving Care

## A CIDP Caregiver's Perspective

By Angela Macropoulos

**B**efore I was personally confronted with being a "caregiver" for my mom, whenever I heard the word, it evoked sweet, noble thoughts. People like Florence Nightingale, generous of spirit and heart, selfless and medically knowledgeable. Or a young, working mom, sandwiched between raising her own children and managing care for an aging parent, understanding of the patient's concerns and always multitasking.

Thank God it wasn't me, I thought. I could never rise to the occasion. I was a corporate tax lawyer, single and living in New York City. While I could do the Internet medical research with my eyes closed (figuratively, of course), what about the laundry, cooking and getting someone to physical therapy?

But since February 2004, that's what I've become—a caregiver for my 77-year-old mom, who has severe chronic inflammatory demyelinating polyneuropathy (CIDP). I can now rattle off the acronym CIDP as though it's been in my life for years. Truth is, when someone you love becomes seriously ill, often the medical learning curve is dramatically shortened.

As much a journey as it has been for my mother (who until two years ago was fiercely independent), it's been a long road for me, too.

There are no travel guides for this metaphorical road trip, and, yes,



everyone's caregiver story is dependent upon such things as the nature of the disease, personality of the afflicted, siblings, spouses and outside help. But I'd like to share some things I've learned thus far. My nuggets of experiential wisdom will undoubtedly change over time, but if anything I share below resonates with one reader, then, as Martha Stewart says, "It's a good thing."

**The diagnosis is the starting point; it's not the whole journey.** Particularly with diseases that require immune globulin for treatment, the nature and progression of the disease is not easily mapped. In fact, most doctors (even specialists) can't tell

either you or your loved one what's going to happen, how any impairment can definitely be staved off, how the patient will feel in two years, much less five. So, you and your loved one do your reading, and ask the docs lots of questions, but get on with it. The sooner you reinforce in your loved one that there's a whole life to be lived beyond the diagnosis and if, in turn, he or she embraces a positive attitude, all the better.

**Don't expect friends and employers to really understand what you're going through.**

Since I'm an only child, my friends are my extended family of support. While they sympathize, unless and

until they have faced similar situations, they can't get the full picture. My advice is don't have a pity party. Just accept it, and be grateful for the love and friendship you get. As for bosses, my general advice is to be judicious in what you say about the specifics of the disease and care. You may be tempted to rattle off a litany of all the things you are doing to validate your actions or time away from work, but you may be on a slippery slope of too much disclosure for no benefit. The important thing is that your boss should know: (a) your caregiving is an important life choice that you are making for a loved one, and (b) while emergencies happen, you will do and act like a professional.

**Yes, there are external sources of help, but start with good family communication.** When my mom was finally diagnosed with CIDP after two months of hospitalization and rehab (ruling out lupus, polymyositis and seemingly every neurological disease imaginable), she came home to a veritable welcome wagon of support. Through the New York-New Jersey Visiting Nurse Service, social workers and home healthcare aides just showed up at the door. Mom left her house for the hospital walking but returned home in a walker and wheelchair. I went from living in my New York City brownstone apartment to returning to my childhood home. I was encouraged, however, because it seemed as though there was a great elder care social support system that was going to help me help Mom adjust to a new life at home.

But like the adage, "if it seems too good to be true, it probably is," it was. The reality was that these people came under a "plan of care," but the duration of the help was dictated by Medicare guidelines, which are limiting. There was little guidance on planning for assistance after the entourage left. Although my mom has had nursing and homecare assistance since her initial return home, we've been learning and continually adjusting to how much help she needs, such as cleaning or putting on shoes. My mom and I have always communicated directly and openly, but I'm doing my best to listen and watch carefully to see what her needs are and how much I can supply without breaking. Being back in her home has been good for her and frustrating too (since she can't navigate stairs without a "boost"), but talking—and more talking—about what is most helpful and how often she needs it is critical.

**Planning for immune globulin infusions.** The first time my mom got an infusion, I was so nervous because I assumed it was like a chemotherapy drip. I didn't know

what side effects, if any, to expect. Turns out I was just overly anxious. But there are small things that I make sure happen when Mom gets her biweekly infusions. For the first year, Mom got her infusions in the neurologist's office. The good news was that the infusion room was populated with only neuropathy patients. It was as much a support group as clinical treatment. The bad news was the 45-mile drive and day off from work for me.

One of the things I learned is that whether at home (where she gets infused now, still biweekly) or at a hospital or doctor's office, it's important to do a few simple things to make the infusion drama-free. First, be sensitive to whether a simple painkiller such as Tylenol might be helpful to take before the drip to ward off fever or pain. When my mother takes one Tylenol right before the treatment, she sleeps better that night and her arm doesn't swell up from the intravenous line. Second, make sure that the patient has easy access to a bathroom, particularly after the infusion is done. And most important, make sure the balance of the day is not chock-full of appointments or travel. Seeing how my mom has more vigor the day or two after an infusion, I credit the rest she gets on actual infusion days for maximizing the treatment.

**Which brings me to... always remember, it's the patient's body, not yours.** Time and again I have to repeat this mantra to myself. One of the first lessons of being a good caregiver or patient advocate is to acknowledge and accept that occasionally your loved one just doesn't want to go forward with certain protocols or treatments. Sometimes it's just too exhausting or frustrating for them. For example, on days when my mom tells me she's just not game for physical therapy (PT) in the rehabilitation center, I'll cajole her to go, to measure if she just wants to play hooky because she thinks she can get away with it. But like a tuning fork, I've got the ear for the truth, and I now know by looking and listening to her that there are days when spending one hour on machines exercising might tire her for days after. In those cases, PT might do more harm than good. It bears repeating that it's the patient's body and well-being—physical and mental—that's at issue. A caregiver, particularly a child or spouse, must honor that, while still trying to find the right balance of appropriate care.

I may learn new lessons in the future, but at this point, my caregiving experience has already provided me tremendous lessons in acceptance, humility and, above all, grace. 🍷

# Everyone Has a Story and This Is Susan's

By Carol K. Miletti



Susan Nissen received her bachelor's degree from North Dakota State University in Fargo and her medical degree from the University of North Dakota Medical School in Grand Forks in 1991. She did a four-year residency at the Mayo Clinic in Rochester, Minn., and, in 1995, began working in her chosen field of physical medicine and rehabilitation. A very athletic and healthy young woman, Susan was married in 2001 and, by 2003, was expecting her first child. Life could not have been any better, so she never saw this one coming.

Shortly after she gave birth to her daughter, Kathleen (now 2 years old), Susan became very sick. She was pounded with recurrent and relentless infections, which kept escalating instead of backing off as they should with medication. For more than a year, Susan had to deal with a range of ailments: urinary retention, bladder and kidney infections, high temperatures, sinus infections, influenza, shingles and a bout of coughing that was so intense she broke a rib — but still she received no definitive diagnosis. She was shuffled from doctor to doctor, and felt no one was listening.

As a physician, Susan knew something was very wrong, but getting to the cause of her health problems was not an easy task. Not knowing what else to do, she finally went to the Mayo Clinic, where she was diagnosed with common variable immune deficiency (CVID). Susan felt as though someone had finally listened to her and actually understood her problem. She and her husband, Dana, felt so relieved to get a diagnosis, they were hopeful that they would now be able to lead a better life.

When Susan began receiving intravenous immune globulin treatment (IVIG) to treat the CVID, she believed her health problems were solved. Unfortunately, following her third infusion, she became ill and ended up in the hospital with aseptic meningitis. By the end of this ordeal,

Susan had lost 20 pounds, along with most of her energy—and some of her optimism. Soon afterward, she began administering immune globulin subcutaneously (under the skin), to better control the speed of the administration and avoid the IgG level drop-offs between IV infusions. Once again, she was hopeful she was on the road to better health.

Today, although Susan's health is improved, she is still challenged with relentless fatigue, joint pain and recurrent infections, but her daughter helps keep her going. When Susan is feeling her worst, being able to enjoy the smiles and kisses she gets from Kathleen provides the best medicine, and Susan's husband serves daily doses of optimism and hope with his love and caring.

Susan senses that many of her friends remember her as the energetic, athletic woman she used to be, not the fatigued fighter she has become. Consequently, she has a smaller, closer network of friends who truly support and energize her with the inspiration to have a positive attitude toward life, despite her fear of more serious complications of CVID. All she really wants is to be healthy again and chase her active 2-year-old; to get back to work being a healer, not a patient; and to pursue her athletics and career. But Susan knows her return to normal activities will have to be done by putting one foot in front of the other, by walking before she runs.

When Susan does put on the "white coat" once again, she knows she'll remember an important lesson: to listen to the patient. It wasn't until she took the bull by the horns and became a proactive patient that she finally got her answers, and she now knows that the patient can actually provide the doctor with the diagnosis! ■

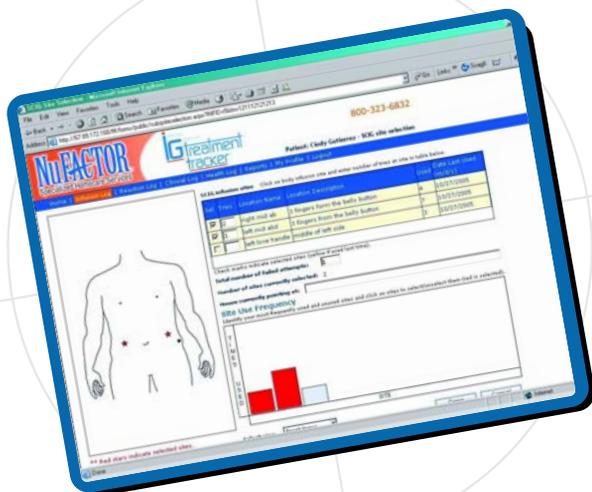
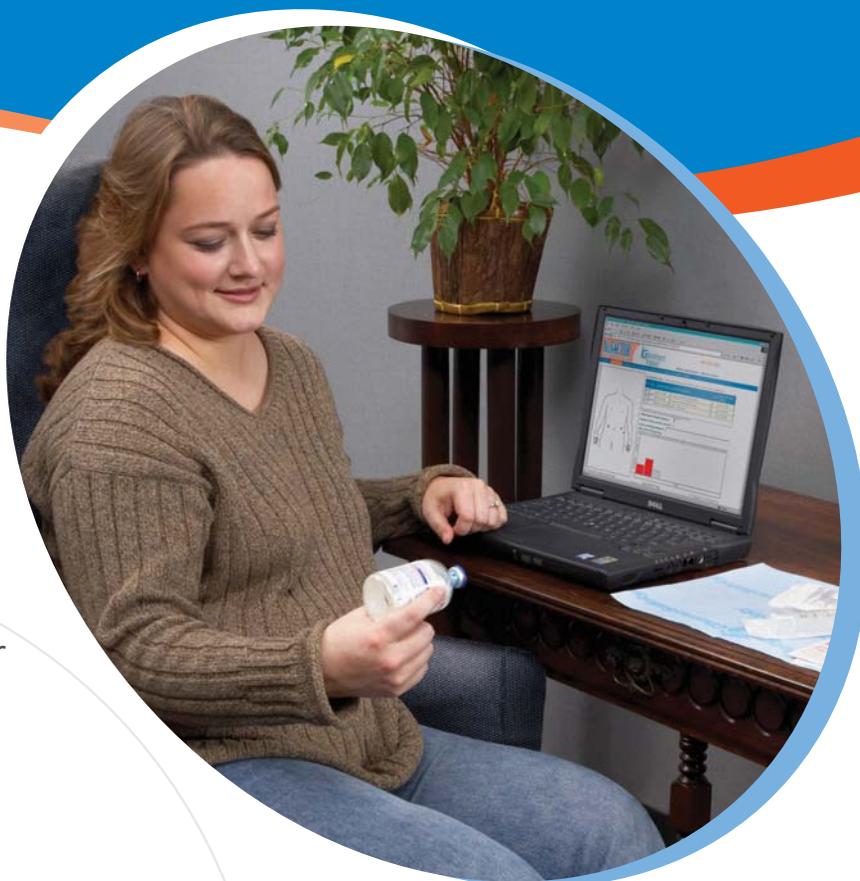
*Note: As you read this, Susan and her family have moved to Minnesota for a better job and better healthcare. Susan is in a new position, practicing her medical specialty again, and continuing her journey to health.*

# Living with an immune deficiency can be challenging

Make your life easier with

**IG treatment**  
**tracker** 

Immune Globulin Treatment Tracker is a secure, web-based system that allows you to easily record, track and report your home IG therapy.



## IG Treatment Tracker gives you:

- Your own private web pages for documenting your therapy
- A complete record of your healthcare—without stacks of paper
- A body image map to identify exact IG administration sites
- An accounting of the amount and rate of your IG treatment—and any changes or reactions
- A record of lab and test results
- Printed reports to share with your healthcare providers
- Secure storage and retrieval of your information whenever you want it

IG Treatment Tracker is a complimentary service for NuFACTOR's homecare patients.  
Call us today for more information: **800-323-6832**

**NuFACTOR**  
Specialized Homecare Services

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

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

# Everything You Ever Wanted to Know About...

## ...Guillain-Barré Syndrome (GBS)

### Websites and Chat Rooms

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

### Online Pamphlets

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

## ...Myositis

### Websites

1.  **THE MYOSITIS ASSOCIATION**  
The mission of The Myositis Association, [www.myositis.org](http://www.myositis.org), is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. 202-887-0088
2. 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>

## ...Peripheral Neuropathy (PN)

### Websites

1.  **THE NEUROPATHY ASSOCIATION®**  
The Neuropathy Association, [www.neuropathy.org](http://www.neuropathy.org), is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association's mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, advocate the need for early intervention and support research into the causes and treatment of neuropathies. 212-692-0662
2. The National Institute of Neurological Disorders and Stroke has diverse topics about PN on its website at [www.ninds.nih.gov/disorders/stroke/](http://www.ninds.nih.gov/disorders/stroke/).

3. To learn about PN, how it is classified, the symptoms, causes and treatments, see the Peripheral Neuropathy Fact Sheet available at <http://www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm>.

### Support Groups

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

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

### Websites and Chat Rooms

1.  **IMMUNE DEFICIENCY FOUNDATION**  
The Immune Deficiency Foundation (IDF), [www.primaryimmune.org](http://www.primaryimmune.org), is dedicated to improving the diagnosis and treatment of PIDD through research and education. 800-296-4433
2.  **JM**  
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
3. The National Institute of Child Health and Human Development (NICHD), [www.nichd.nih.gov/](http://www.nichd.nih.gov/), is part of the National Institutes of Health. Go to the "Health Information and Media" tab on the website and do a search under "primary immunodeficiency."
4. The American Academy of Allergy, Asthma & Immunology, [www.aaaai.org](http://www.aaaai.org), has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.
5. Baxter's website, [www.immunedisease.com](http://www.immunedisease.com), offers in-depth information on immunology, PIDD and treatment with intravenous immune globulin.
6. The Michigan Immunodeficiency Foundation, [www.midf.org](http://www.midf.org), seeks to improve the quality of life for Michigan residents affected by PIDD.
7. The International Patient Organization for Primary Immunodeficiencies (IPOPI), [www.ipopi.org](http://www.ipopi.org), promotes the worldwide improvement in the care and treatment of PIDD patients.
8. To connect to a PIDD message board, go to [www.jmfworld.com](http://www.jmfworld.com).
9. To chat with peers on IDF's Forum, go to [www.primaryimmune.org](http://www.primaryimmune.org).

# Everything You Ever Wanted to Know continued...

## Online Pamphlets

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

## ...General Resources

### Product Information

1. To learn more about Vivaglobin—the subcutaneous immune globulin (SCIG) recently granted FDA approval—go to: [www.vivaglobin.com](http://www.vivaglobin.com).
2. For more information about the new 10% IVIG solution Gammagard Liquid, go to [www.gammagardliquid.com](http://www.gammagardliquid.com).
3. Learn about IVIG treatment with Gamunex at [www.gamunex.com](http://www.gamunex.com).

### Other Organizations

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

## Books and Articles

1. "21st Century Complete Medical Guide to Primary Immune Deficiency, Severe Combined Immunodeficiency (SCID), Chronic Granulomatous Disease (CGD), for Patients and Physicians," by PM Medical Health News, contains federal government clinical data and practical information for patients and physicians.
2. "A Handbook for Care Givers," by Helen Rummelsburg, gives an account of caring for her husband and offers helpful hints for patients and caregivers. Available at the GBS website bookstore at [www.gbsfi.com](http://www.gbsfi.com).
3. "Anatomy of an Illness," by Norman Cousins, is a bestseller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body's capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
4. "Bed Number Ten," by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
5. "Caring for a Child With GBS," by Patricia Schardt, is a short guide written by a mother of a child with CIDP. Available at the GBS website bookstore at [www.gbsfi.com](http://www.gbsfi.com).
6. "The Confused Consumer's Guide to Choosing a Health Care Plan: Everything You Need to Know," by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.
7. "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.
8. "If You're Having a Crummy Day, Brush Off the Crumbs!," by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.
9. "Inclusion-Body Myositis and Myopathies," by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.
10. "Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration," by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.
11. "Managing Pain Before It Manages You," by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.
12. "Medifocus Guide to Peripheral Neuropathy" is a guide to current and relevant PN research, organized into categories for easy reading.
13. "Myositis—A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References," by ICON Health Publications, is a three-in-one reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.
14. "No Laughing Matter," by Joseph Heller (the best-selling author of "Catch-22"), who teamed up with Speed Vogel, his best friend, to describe Heller's battle with and triumph over GBS. ➤

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

15. "Not Dead Yet: a Long Strange Trip From Doctor to Patient and Back Again," by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.
16. "Numb Toes and Aching Soles," by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
17. "Numb Toes and Other Woes," by John Senneff, is the second in a series of three books. It focuses on clinical findings and treatment strategies for PN.
18. "Nutrients for Neuropathy," by John Senneff, the third in the Numb Toes series, is focused exclusively on nutrient supplementation as a means for managing PN.
19. "The Official Patient's Sourcebook on Inclusion Body Myositis," by James N. Parker (Editor) and Philip M. Parker (Editor), is a reference manual for self-directed patient research.
20. "Pride and the Daily Marathon," by Jonathan Cole, describes how Ian Waterman was suddenly struck down at work by a rare neurological illness that deprived him of all sensation below the neck, and how he reclaimed a life of full mobility.
21. "Pronoia Is the Antidote for Paranoia," by Rob Breznsny, explores the best way to attract the blessings that the world is conspiring to give us.

#### 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)

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

#### Pump and Needle Websites

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

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

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

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

---

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

# IG Treatment Tracker Empowers Patients

By Alma Lucy Morales

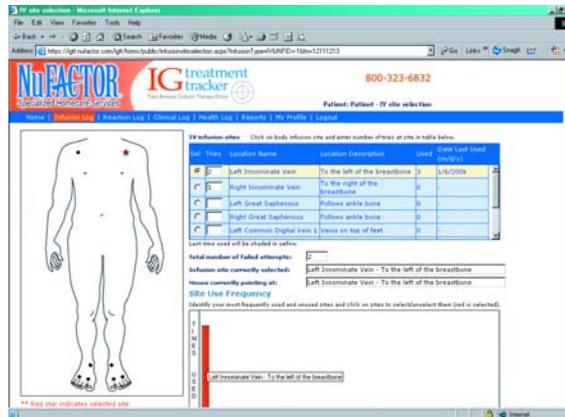
NuFACTOR, a homecare services company, has launched a unique system for patients to track their immune globulin therapy online on their own secure web pages. The system, IG Treatment Tracker, allows patients to maintain comprehensive infusion and health logs, including such information as product lot numbers; infusion method, amounts and rates; exact administration sites on a body image; infusion attempts and reactions; and lab and test results. IG Treatment Tracker also has a reporting function, so patients can retrieve their stored information whenever they want and share it with their healthcare providers.

"IG Treatment Tracker puts patients in control of their homecare therapy," said Kimberly Duff, clinical nurse coordinator at NuFACTOR, "and it improves communications with their healthcare providers. IG Treatment Tracker captures a complete view of the patient's IG treatment and related health issues, allowing them and their physicians to more easily manage their treatment."

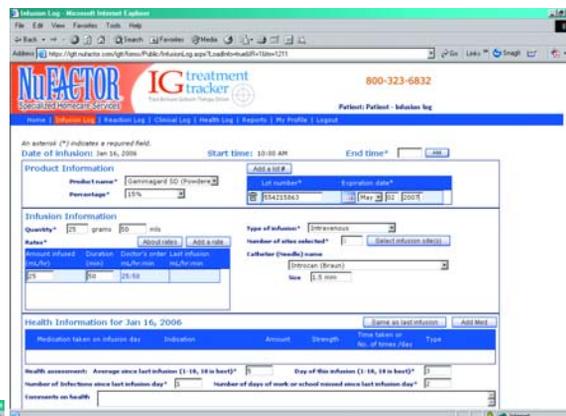
IG Treatment Tracker stores all patient information in a private, HIPAA-compliant record that patients can access and update as often as they desire. The web-based system does not require the downloading of any additional programs; the only requirement is Internet access.

"We are very pleased to be able to provide IG Treatment Tracker as a complimentary service to our patients, and we couldn't have created it without them—they told us what they needed!" said Duff. "The freedom and control the system offers to help manage their own IG treatment, and to give their physicians up-to-date information, is really empowering."

For more information about IG Treatment Tracker, visit [www.nufactor.com](http://www.nufactor.com) or call NuFACTOR at 800-323-6832.



The Infusion screen allows you to track your infusion sites on a body map.



The Infusion Log displays a record of detailed product, infusion and health information.



The Clinical Log maintains an ongoing record of vital statistics and test results.



The Health Log records your ongoing health assessment.

# Writing for Healing

By Carol K. Miletta

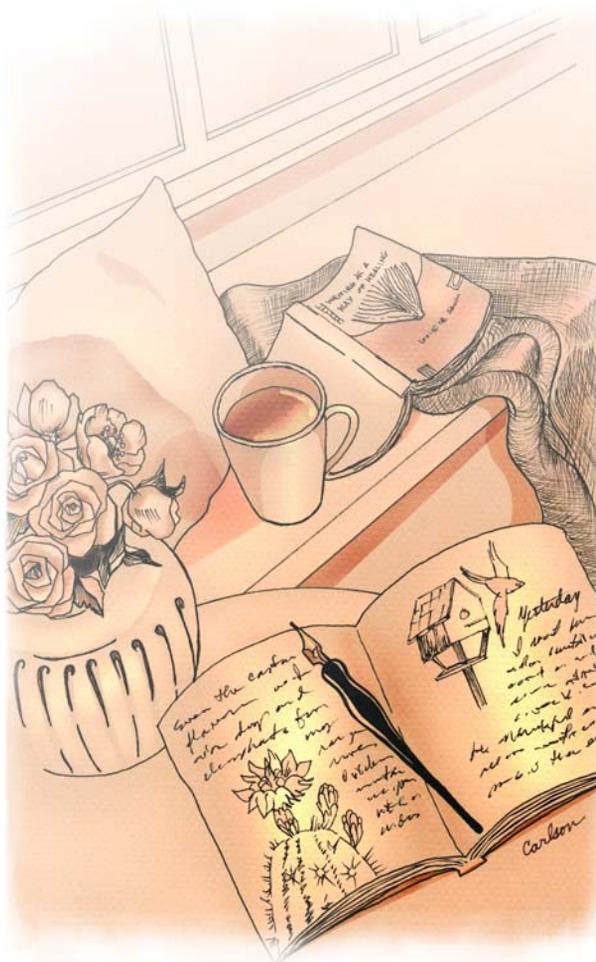
I woke up one morning toward the end of May so incredibly depressed that I did not know how to deal with what I was feeling or even how to get through the day. The trigger for this depression had been the cancellation of a birthday dinner for my son, due to my ill health. And, while I had gotten used to canceling events for health reasons, I had been particularly looking forward to this day. Thus, the beginning of my downward spiral.

I was lucky enough to be aware that I was depressed and acknowledged it to my husband; he was smart enough to insist on an immediate visit to my psychologist. And guess what? She suggested I start writing. First, she had me write a letter to myself (it was not a very kind letter), and then she mentioned a local writing class that might be of help to me. I had no idea how writing could possibly help me through this, but I guessed I was about to learn another life lesson.

To summarize my writing journey, I went from “woe is me” to “I’m so happy” in about eight weeks. What I learned was pretty powerful, and I would like to share some of it.

## Why should we write to heal ourselves?

There have been countless studies in the medical, psychological and alternative-healing fields that prove writing can relieve stress, improve our outlook and our



attitude, reduce our suffering, and help us heal. I’m not suggesting that you will recover from your illness by writing, but according to Deepak Chopra, “health is not just the absence of a disease. It’s an inner joyfulness that should be ours all of the time—a state of positive well-being.” If we can put our negative feelings aside through writing about them, we can get on with our lives. Yes, we’ll still have ups and downs, but a certain weight will be lifted from us. Writing can help us transform ourselves from victims to survivors by recording fears, concerns and problems, and by focusing on our internal life instead of our physical life.

Louise DeSalvo wrote a book called “Writing As a Way of Healing.” In it DeSalvo suggests, “writing that describes traumatic or distressing events in detail—how we felt about these events then and feel about them now—

is the only kind of writing about trauma that clinically has been associated with health.”

Have I convinced you yet that you will benefit from this writing exercise? If so, let’s get started.

## Where do we start? This seems somewhat overwhelming.

First of all, just start writing—anything, anywhere.

You might actually be writing already and not realize it. Do you keep a diary or journal? What about chatting with an online support group? Do you send emails to friends and family? Are you venting or giving advice? If so, then you are already writing, and there are ways to

make even better use of your writing.

You could do what I did to start: Write a letter to yourself, and plan on being surprised by it. You could write a letter to anyone about anything, but remember, you don't have to send it.

Write a memoir about a day or event, and use detail. Dig deep down inside and write the things you think about in the middle of the night when you can't sleep.

Do you have a special place you like to write? Where the sun shines in just so? A table, your bed, your computer? How about your favorite pen or pencil, a particular type of paper? Whatever it takes, what is important is to relax while writing and just let it flow.

Now, pay attention to what is occurring while you are writing. Are you stressed, are you crying, are you scared of what you're saying? Pay very close attention to this. You are doing it now, you are writing. Have patience. It will get better with time. Stay committed to your writing. Try writing at the same time every day for 20 minutes. Write what you feel you need to write, what you want to write. How about what you don't want to write? What troubles you or scares you? What really makes you happy?

Do you want to write about how much you miss the old you, the one who was there before you got sick? What do you miss about life then? What opportunities have you had to give up due to health? Write about everything that you are unhappy about.

In "Dear Heart, Come Home" by Joyce Rupp, she writes about letting go of feelings. "You let go of people and you let go of expectations, and if you're lucky, you find a way to do it without letting go of hope."

Think what you'll learn about yourself by writing all of this down! Below are some ideas to get you started. After each phrase, just fill in whatever comes to mind.

*Since I got sick...*

*What I miss most is...*

*Suddenly, ...*

*I was making plans...*

*I felt the weight of my illness and...*

*Once upon a time, ...*

This next one will make for some excellent reading: Write your own obituary exactly the way you would like it to read—you can even make some of it up. This is not a sad adventure; it's actually a pretty enlightening one. You may end up having a better appreciation for yourself when you're finished.

### Now let's have some fun.

You've spent some time getting the sad and ugly things out, so it's time to look at the good things that have come from your illness.

Countless authors tout the benefits of using humor to aid in the healing process. Comedian Mike Myers has said that when we laugh at the comic slipping on a banana peel, we are laughing at our own mortality. Try writing about something funny, something everyday or ordinary that you can make humorous. Invite yourself, but don't force yourself, to write of unexpected humor. You see it everywhere.

Now start paying closer attention to life events and write yourself silly. Write about your bed, your medicine, your body or soul. Give them detail, color, texture, smell, taste—and humor. Get carried away. Isn't that what humor is all about? Remember: That which does not kill us, only makes us stronger. So use some humor to get stronger every day.

### Now let's get serious.

You've probably heard that there is a time to be healthy and a time to be sick, from either Ecclesiastes or the Beatles. Well, now is the time to start to count our blessings. There is a long list of them—from our loved ones to the medicine we take to help us get through it all. Start a gratitude list. Writing has been proven to improve our immune system function, so just think what a list like this will improve!

Are you thinking you might be beyond learning to write? Consider this: Cicero did not begin writing until age 60! ■

---

*Just in case all of this free-form writing leads you to something you would like to share, please email us at [editor@igliving.com](mailto:editor@igliving.com).*

# Hey Kids—It's IG Day



Photographed by Tom Henderson

Designed by Allan Bean

Written by Kit-Bacon Gressitt

Every three weeks, Dayna Fladhammer puts her children in the van and races the dawn from Las Vegas to Mattel Children's Hospital at UCLA. It's a four-hour journey that brings the three of them to a place that, though fleetingly scary, feels mostly safe; a place that provided Dayna the support she desperately craved in the days when Charlie and Katie were newly diagnosed with primary immune deficiency disease.

"Back then, I might have gone over the edge if it weren't for this place and these people," Dayna chuckles.

Every three weeks, Jenelle Scott loads up a rhythm section of thumping medical equipment, rolls her son Noah into the same clinic, and turns the treatment room floor into a playground of colors for Noah's fading eyes.

"He's an old soul," Jenelle says of her 8-year-old, immunodeficient son who will sweetly, slowly succumb to Hurler's syndrome, an enzyme deficiency. "We just enjoy each day with him," she says stolidly.

Every three weeks, nurse Jennifer Richlin greets the lot of them—with hugs and kisses, a ubiquitous supply of forms, and the compassion to engender the trust of kids she'll soon be sticking.



Then they all settle in for a day of immune globulin infusions, embraced with love and laughter, brief tears and not-too-bad tantrums, and the powerful magic of kindred souls. They are in this together, and together they make it work.



But first they wait,  
and play, and gnosh ...



... and wait a little more for the dreaded moment  
that no manner of distractions can dispel.  
The moment of reckoning between parent, child, nurse and needle.



Some days are easier than others; some are more painful for the parent than the child. Regardless, the needle stick is part of the infusion, and neither child nor adult wants it.



"Charlie was freaking out one day," Dayna remembers, "and then I was freaking out. Thank God for Jenelle! She reminded me that he's a kid; it's normal for him to freak out when he's getting a needle."



And when the needles and taping and checking and hugging are all done, the moment passes into pursuit of other distractions, while immune globulin slowly pumps into their young veins.

Immunologist Robert L. Roberts concedes to a draw on the “you go first” contest, one of many in a pediatrician’s tool kit for finessing a reluctant child’s participation in an exam.





The favorite nurse checks on her patients—again and again.



Skittles become the perfect reward—  
“Yes, on treatment days, even at 8 in the morning.  
Hey, at least they’re fruit flavored!”

The portable DVD player delivers songs of comfort, well remembered.



But as the day slowly  
flows on, even being  
the center of attention  
becomes a bore.





Then it's more hanging out while the precious proteins continue pumping into their precious bodies—to help keep them strong and resistant to infection like the superheroes in their movies...





...until it is done, the very last drop of miracle liquid hits its mark,  
and the children visit the toy closet to pick their  
"take-home" rewards for being brave.



And Dayna, Jenelle and Jennifer share the brief luxury of just enjoying each other—the intimacy of chronic disease. “When you need a lot of support,” Dayna explains, “you give a lot of support.”



Then, at long last, the patients get to go home, antsy and raucous, ready to play and tease, in control of their own destiny—powerful enough to push all the buttons in the elevator!—because, though they are patients today, they are most importantly children.

And so the cycle goes. ■

# 12 Important Questions

## to Ask Before Choosing a Health Insurance Policy

Deciding whether a health insurance policy is right for you is similar to shopping for the right car to buy. The latest model may look appealing, but does it have what you need and does it have the proverbial “bells and whistles”? The same is true when deciding upon a health insurance policy. So, the following are the most important questions you should ask before signing on the line.

- 1. Does the policy cover your chronic illness or condition?**  
You should ask the agent if your chronic illness is covered both for outpatient and inpatient services.
- 2. Does the policy cover the prescription drugs and treatments for your chronic illness or condition?** Sometimes health insurance policies will limit the amount of prescription or treatment coverage allowed for your illness or condition. Make sure you ask if there is a limit on prescription drugs and treatments.
- 3. Is there a waiting period for a preexisting condition, before your condition or illness will be covered and services paid for?**  
This will be important for you in order to plan how you will pay for the service you need during the waiting period.
- 4. Does the policy cover injectables?** At times, health insurance policies will cover prescription drugs, but will not cover injectable prescription drugs. In a similar way some policies cover the administration of blood and blood products, and some do not. Make sure you ask specifically if the policy covers your injectables, infusions, and blood/blood products.
- 5. Does the policy allow you to use an “in-network” provider, physician, and pharmacy and an “out-of-network” provider, physician and pharmacy?** Some policies have what they call in-network
- and out-of-network providers. In-network providers or physicians make cost-saving contracts with the insurance company, which in turn saves you money. If you use a provider or physician outside this group (out-of-network), then you may be responsible for more costs.
- 6. Does their specialty pharmacy have experience providing services to people with your condition?** Believe it or not, sometimes service providers don’t even know how to spell your condition or know how serious it is. They just process your claim in the most cost-efficient manner.
- 7. Does the policy have a lifetime maximum amount or “cap”?**  
If so, how much is it? You need to ask if the lifetime maximum will cover you for a reasonable amount of time. Insurance policies have a limited amount they will pay out during the lifetime of the policy. These lifetime maximums usually range from \$500,000 to \$5,000,000. There are some policies that have no lifetime maximums.
- 8. Is your prescription or treatment charged to a prescription drug plan?** What is the annual maximum (cap) for your prescription or treatment, or is your prescription or treatment charged to the major medical part of your policy plan? Often when the prescription or treatment is charged to a prescription drug plan, the costs do not count against the annual limit or lifetime maximum. If the prescription or treatment is charged against your major medical,
- then it will count against your lifetime maximum amount of coverage.
- 9. Does the policy have a deductible? How much?**  
The deductible is the amount of money you pay in costs before the policy starts paying the claims.
- 10. Does the policy have an “out-of-pocket” amount?**  
How much? The out-of-pocket is the amount you have to pay toward your co-payments until your insurance covers the cost 100 percent.
- 11. Ask the company if they will inform you of any changes in your policy in writing.** In most states it is the law to provide to you, in writing, any changes to the policy.
- 12. Ask the company if they will send you a policy for your files so you can read the contract you have with them.** Make sure you keep a copy of the policy with your important papers. Make sure you read and highlight the policies that apply to your condition and treatment. ■



*Reprinted with permission from Patient Services Incorporated.*

# Let's Talk!

By Shirley German Vulpe, EdD

**L**et's Talk is an opportunity to share our experiences of living with a condition that requires immune globulin therapy. It behooves us to learn as much as possible about all the ramifications of our illnesses and their IG treatment, and we can learn from one another. In each bimonthly issue of IG Living, we will share here how one or another of us has handled an aspect of our illness or immune globulin therapy—and, perhaps, discover a new solution that could profoundly affect our lives.

For this inaugural column, I interviewed my friend Nancy Hoffman about how she solved the problem of being denied health insurance coverage as a consequence of her immune deficiency.



**Shirley:** Nancy, how did you lose your health insurance?

**Nancy:** I was working when I got ill. I had pneumonia, bronchitis, all kinds of things, and then I was finally diagnosed with hypogammaglobulinemia, a primary immune deficiency disease. I had to quit work because I was so sick. After I quit, my health insurance ran out. I then paid for health insurance through COBRA [Consolidated Omnibus Budget Reconciliation Act]. This lasted for about a year. It was a devastating time, and I had trouble dealing with it all and being so sick at the same time.

**Shirley:** What did you do when the COBRA ran out?

**Nancy:** I tried to obtain health insurance through many different companies. They all denied me coverage because of my immune deficiency.

**Shirley:** Then what did you do?

**Nancy:** Panic! Then I asked around—everywhere. I had received

*If you have a question, comment or experience to share for a future column, email it to us at [editor@igliving.com](mailto:editor@igliving.com) or call us at 800-843-7477 x1143.*

three denials, which allowed me to go to the state for help. I can't remember exactly who told me about it, but I was given the telephone number of the California state plan to provide health insurance for people who are unable to get insurance [because of a pre-existing condition]. It is called MRMIP [California State Major Risk Medical Insurance Program]. I called them and they said they would sign me up, but it would take six months. The problem is that with an immune deficiency, you can't wait through the process before receiving treatment, so I was able to get on a medically indigent program, a Medi-Cal program called Medically Needy Medi-Cal. They enrolled me, and I then had to go to the county hospital in

Riverside. I saw doctors there and received my infusions. All treatments and medicines were paid for. It was very demeaning, but I did get very good care. The doctor there helped me eventually to get homecare.

I felt like the scum of the earth. I was embarrassed and ashamed. In one of my many interviews, a very kind social worker, I think, told me not to feel so badly. After all, I had worked and paid into the system and that's what they were there for—to help people like me. Nevertheless, it was a nightmare, piles of paperwork, travel to hospital and sitting for hours, telephone call after telephone call. It is very difficult when you are feeling so sick, but you have to be your own advocate and do what you have to do to get to the next stage. As an immune deficient patient you have no other option. The programs are there. They are difficult to access. It's very time-consuming, and it

is difficult to make yourself do it, but you have to!

**Shirley:** So what was next?

**Nancy:** Luckily, my case was expedited and I was put onto the state's high-risk program, MRMIP. They offered me a choice from many insurance programs. I chose a Preferred Provider Plan [PPO] from Blue Cross because I wanted to choose my doctors and where I received my gamma globulin. HMOs [health maintenance organizations] were available also. I was covered by that PPO for three years. It cost \$700 to \$800 a month. After three years, I was put into a post-graduate program, which is even more costly, about \$1,000 a month. I know it is expensive but it is less costly than buying the immune globulin outright, plus I have to have coverage for other medical illnesses, emergencies or accidents. My husband and I just have to look at it this way, and fortunately we have been able to pay the price. It has been very difficult at times, but somehow we have managed.

**Shirley:** So where are you now?

**Nancy:** I'm not sure. I am expecting a notice anytime now from my insurance company—each year the rates go up. I may have to change programs. [...] It is very important that I have coverage for all types of illnesses as well as my immune deficiency and immune globulin. I will continue to do everything I need to do to get the best coverage I can. As I said before, we must advocate for ourselves. Being this sick really clouds your brain, but you really have to be your own advocate. That's why it's important to get this information out, because it needs to be available to people in the same position I was in. The help is out there: Don't give up and don't take "no" for an answer. Get on the computer, go to the library. Be your own advocate, and just go, go, go! You'll be surprised by the help you'll get. ■

## Public Health Insurance Information Resources

1. The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a federal program that is applicable in all states. COBRA offers workers who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances, such as voluntary or involuntary job loss, reduction in the hours worked, transition between jobs, death, divorce and other life events. Visit [http://www.dol.gov/ebsa/faqs/faq\\_consumer\\_cobra.html](http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.html) or talk to your employer's human resources department for more information about COBRA benefits.
2. Major Risk Medical Insurance Program (MRMI) for Californians: <http://www.mrmib.ca.gov/> or call 800-289-6574. This line will be answered by a Blue Cross representative. Blue Cross has been designated by the state of California to take applications for the MRMI.
3. University of California Medical Center provides an overview of all health insurance programs. Log on to [http://cc.ucsf.edu/crc/insurance\\_overview.html](http://cc.ucsf.edu/crc/insurance_overview.html) or call 415-885-3693 for additional information.
4. Medicaid is a federally funded program available to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. Learn more about Medicaid at [www.cms.hhs.gov/MedicaidGenInfo](http://www.cms.hhs.gov/MedicaidGenInfo).
5. Medi-Cal (California's name for the state's Medicaid programs) is administered by the California Department of Health Services, and services are provided in each county. Call the Department of Health Services at 916-445-4171 to request the telephone number of your county office. There are two programs for people with life-threatening medical conditions in financial need: Medically Needy Medi-Cal and the Medically Indigent Services Program. The social and financial criteria for each program are different. For more information, visit your local county office or visit [www.medi-cal.ca.gov](http://www.medi-cal.ca.gov).
6. The Immune Deficiency Foundation website offers health insurance helpline services. To access the programs call 800-296-4433 or visit [www.primaryimmune.org/services/insure\\_help.htm](http://www.primaryimmune.org/services/insure_help.htm).
7. Patient Services Incorporated (PSI) is a nonprofit charitable organization, primarily dedicated to subsidizing the high cost of health insurance premiums and pharmacy co-payments for persons with specific chronic illnesses and rare disorders. Visit <http://www.uneedpsi.org/index.cfm> or call 800-366-7741 to learn more about PSI's programs.

*Note: Health insurance assistance programs for individuals unable to obtain health insurance due to serious pre-existing health conditions vary from state to state and, sometimes, county to county. This article covers information for Riverside County, California, where Nancy lived when she first received assistance. Questions about health insurance programs available in another state should be addressed to that state's health department. An Internet search will usually provide contact information. If you do not have Internet access, contact the social service department for your local university medical center, or a source quoted in the resource section above may be very helpful.*

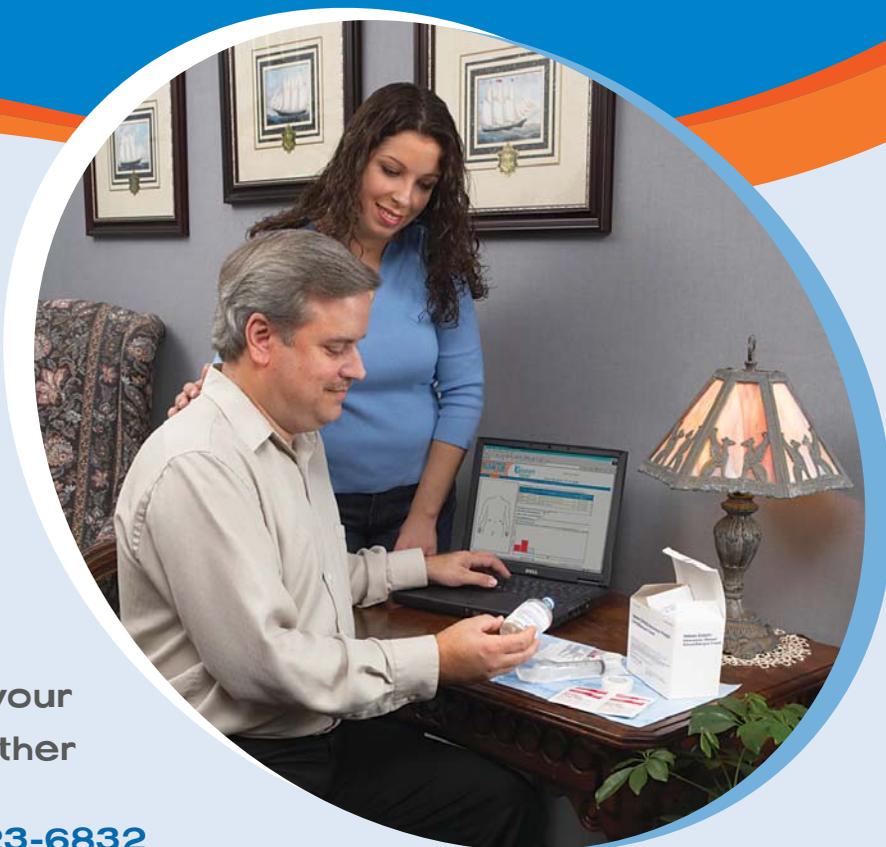
# We know your world

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

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

We know how to make your world work a little smoother

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



**NuFACTOR**  
Specialized Homecare Services

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

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



Subscribe to IG Living — your community magazine at [www.igliving.com](http://www.igliving.com)

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

PRSR STD  
US POSTAGE  
PAID  
PERMIT 1  
TEMECULA CA