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Port Access for IVIG
Another Option

Mother Dolores Hart
Contemplating
Peripheral Neuropathy

Nutritional Immunology
An introduction



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Get the Most from Your Doctor Visit — Some Tips on Page 23

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About IG Living

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

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Where's Our Hero?



This statement was a far cry from the days of yore, when “sickly” family members were often hidden away—a lurking blemish on the social standing of a red-blooded, oh-so-healthy American family: “We need to aggressively become visible, to make people aware of myositis and the difficulties that exist in diagnosis and treatment. ...Our efforts are designed to get attention, to attract a strong spokesperson.” These are the words of Bob Goldberg, executive director of The Myositis Association, the national organization representing patients with this rare autoimmune disease that causes swelling and muscle loss.

Bob is not alone.

You might have read Angela Macropoulos’ comment, in our last issue, bemoaning the void of a star to serve as the voice of peripheral neuropathy: “Without a proactive celebrity face, change is slow, but it is coming,” she wrote. “[P]erhaps someday soon there will be an articulate, notable advocate who will give... all those who suffer from neuropathy hope for more research and better treatment.”

Akin to myositis and peripheral neuropathy, many of the diseases and conditions treated with immune globulin—on and off label uses—just don’t have the draw of well-known afflictions—such as cancer or heart disease, AIDS or spinal cord injuries—because most folks have never heard of them.

Where are the Hollywood glitterati, the charmingly sincere likes of Michael J. Fox, eager to lend their fame to dermatomyositis, X-linked agammaglobulinemia, inclusion body myositis, severe combined immune deficiency, chronic inflammatory demyelinating polyneuropathy, Guillain-Barré syndrome, and on and on? Where is the dashing superhero, swooping in to make household words of these unpronounceable ailments, share a guest spot on Oprah with a CVID patient or two and—the ultimate goal—attract public funding for research to reveal the cause, support earlier diagnosis, prove a better treatment or even find a cure?

We’re still waiting for ours.

In the meantime, what do organizations such as The Myositis Association (TMA) do? They work really hard with minimal staff, minuscule budgets and masses of commitment to increase awareness of their target diseases. They provide support and referrals and information to thousands

of families facing some tough challenges. And, they excel at making do—knowing they need to do more.

“We are a small-budget organization—a little over half a million dollars—dealing with a rare disease,” Bob explained. “We have limited staff to work on advocacy, and it’s hard to be heard, but you must have people working on Capitol Hill.”

So, TMA has taken the Beltway plunge and hired a D.C. consulting firm to help win funding for a patient registry and surveillance survey to monitor patients and their treatment; to encourage Congress to fully fund the National Institutes of Health Autoimmune Diseases Research Plan; and to help balance the allocation of public dollars between competing diseases.

According to Bob, the better known and, hence, better represented diseases “end up getting a disproportionate share of the research dollars. We just want help for people who desperately need it,” he said. “In the end, it’s about justice and fairness.”

And, in the end, when TMA finds its Superman, when the average Joe Schmoie knows the difference between a primary immune deficiency disease and AIDS, when we achieve equitable public funding for medical research—however we resolve to define it—then our readers’ ailments will have come of age.

In the meantime, we’ll continue to rely on Bob Goldberg and his peers, because, though they do not know it, they are heroes. And, they could use your help. To learn more, visit the the patient group websites listed in IG Living Resources.

On another note, we’d like to hear from you! Our new “Readers Write” begins in this issue with a mother’s recounting of the scary road to proper diagnosis and treatment for her young son. For our next issue, tell us what you actually *like* about living with a chronic disease. Really! Send your responses to editor@igliving.com. ■

Kit-Bacon Gressitt, Editor

New Contributing Writers

Dick Sheridan **is a freelance writer who has written about a variety of subjects, including entertainment—but never about a cloistered nun who still belongs to the Screen Actors Guild.**

Quotable: “I’ve done Hollywood stories before, but never with a twist like that. When you hear about something like [his subject’s peripheral neuropathy], it gives me the willies. I just didn’t know that something like a root canal could lead to something like that.”

Ever Fecske **is a 21-year-old student with common variable immune deficiency. Her story is a humorous look at her first infusion, because, she says, how else can you approach something like that?**

Quotable: “I had a sinus infection for 11 days, and when it didn’t get any better I asked my doctor to run all the tests. I knew from the top I had a low count, and I wanted to get to the bottom of it. I knew something was wrong, but I didn’t know there was a name for it. Since then, when I’ve talked to some of my doctors about it, they tell me they had read about it in medical school, but had never met anyone with the disease.”

Jessica Schulman, PhD, **is a registered dietitian.**

Quotable: “I was invited to [write an article on nutrition], but I really didn’t have time. But the woman who asked me to do it emphasized how important it was, and I realized that if I had to do it at 3 in the morning, I’d do it. I wanted to give something back to the community. There was a time when physicians really understood the relationship between diet and the immune system. I don’t know exactly what has changed, but we’ve gotten away from looking at the big picture. With the exception of a malnourished individual, no amount of nutritional advice is going to change immunoglobulin levels, but the three do interact. If you just focus on one, you’re not going to have the optimal health you can have.”

Peak & Trough

As the PCP in your HMO, HIPPA requires me to inform you that your Rx for your CVID will be covered at 80% of AWP up to an OOP of \$15,000.



Diagnostic and Clinical Care Guidelines: A New Resource from IDF

From the Immune Deficiency Foundation

For over 25 years, the Immune Deficiency Foundation (IDF) has been committed to improving the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy. Everyday at IDF, our patient advocate receives calls from patients and their families. They may be searching for physicians, needing insurance help or seeking peer support. However, their requests for information on diagnosis and treatment of primary immune deficiency diseases consistently rank as one of their top needs.

Our Consulting Immunologists Program fosters better treatment information by providing information about specific patient diagnosis, treatment and disease management to physicians. When physicians contact IDF with questions about a particular patient, they are put in touch with expert clinical immunologists who provide free second opinions or consults. Still, these physician requests indicate a need for more information and guidance on care and treatment options throughout the United States.

Survey Results Emphasize Need for Better Outcomes

Statistics from past IDF patient surveys indicated that the average time to diagnose primary immune deficiency disease was 9.2 years. During this delay, 37 percent of patients developed permanent impairments, such

as loss of hearing, pulmonary function, digestive function, mobility, vision or neurological function.

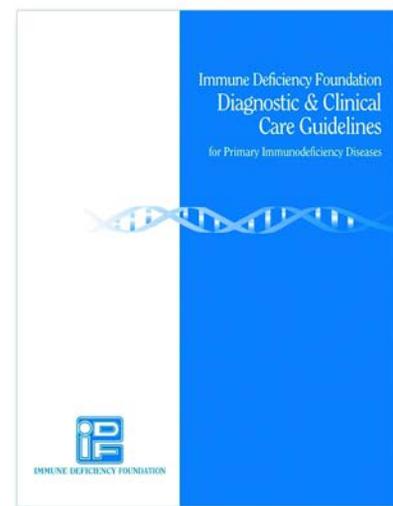
These health issues may be a result of delayed diagnosis. Additional results also reported access to specialists was limited by type of health insurance. Twenty-one percent of patients surveyed had treatment delayed, 11 percent were not able to see a specialist as often as needed and 17 percent had treatment denied by insurance carriers.

IDF Fulfills a Vital Need

"Hearing the needs of patients, their families and healthcare providers, combined with the patient survey results, we knew we had to be more aggressive in providing information for patients with primary immune deficiency diseases," said Marcia Boyle, president and founder of IDF. As a result, we are proud to present The Immune Deficiency Foundation Diagnostic and Clinical Care Guidelines for Primary Immunodeficiency Diseases."

In partnership with leading immunologists, IDF spearheaded the development of the guidelines to enhance earlier diagnosis, improve health outcomes and increase access to specialized healthcare and optimal treatment for patients with primary immunodeficiency diseases.

Under the able leadership of Dr. Rebecca H. Buckley, from Duke University School of Medicine and chair of the IDF Medical Advisory



Committee, an expert panel of 22 immunologists was formed. The panel identified evidence-based diagnostic and clinical care guidelines for select primary immune deficiency diseases.

"We tapped much expert knowledge and experience to produce these comprehensive, evidence-based diagnostic and clinical care guidelines for the primary immunodeficiency diseases." Dr. Buckley explained. "The practical information, invaluable for patients and healthcare providers alike, is a major step for IDF to better inform and educate everyone touched by these diseases."

The Guidelines include recommendations, strategies and information to assist physicians and patients in making educated decisions about appropriate healthcare for their primary immune deficiencies. The publication addresses a comprehensive list of issues, and each chapter also includes frequently asked questions.

For a free copy of the Guidelines, visit www.primaryimmune.org or call IDF at 800-296-4433. ■

Development of the Immune Deficiency Foundation Diagnostic and Clinical Care Guidelines for Primary Immunodeficiency Diseases was funded by an educational grant from Talecris Biotherapeutics.

Nutritional Immunology: An Introduction

By Jessica Schulman, PhD, MPH, RD



We have known for years that diet plays an important role in supporting a healthy immune system. Nearly a century ago, doctors wrote articles asserting that “consumption and pneumonia germs cannot establish themselves in a well-nourished body,” (1911, Washington Post). It has been more than 30 years since Dr. Jean Meyer, professor of nutrition at Harvard University, pointed out that “measles hardly ever kills a well-fed person,” (1974, Washington Post).

Today, nutritional immunology is a recognized field of study, and cutting edge researchers are working on understanding how nutrition status, infections and the immune system interact to affect health and disease. The main focus of this article is to offer some basic information about this emerging area of medicine.

For the immune system to function effectively, the body must have access to sufficient nutrients. If an individual is undernourished, simple skin tests, called delayed hypersensitivity tests, can point to immune dysfunction even in the absence of a true T-cell defect. Nutrients can be classified into micronutrients or “small” nutrients (i.e., vitamins and minerals) and macronutrients or “big” nutrients (i.e., fats, protein, carbohydrates). I will discuss each of these classes of nutrients in turn.

What Vitamins and Minerals Are Important?

It is outside the scope of this article to provide specific dietary recommendations for each micronutrient, but there is a considerable amount of research that highlights the importance of adequate folic acid, vitamin A, vitamin B6, vitamin B12, vitamin C, vitamin E, copper, iron, selenium and zinc. Recently, scientists have reported that vitamin D has therapeutic potential in modulating immune-mediated diseases. People living with immune deficiencies and malabsorptive conditions are highly prone to micronutrient deficiencies. For such people, whole foods alone, even if carefully chosen, may still fail to provide adequate vitamins and minerals. In such cases, vitamin supplements may be warranted.

If a Little Is Good, Is a Lot Better?

No! On the contrary, excessive intake of micronutrients can actually impair immune function. For example, one study showed that immune function improved when patients were given zinc supplements. Other studies, however, do not show any improvement and determined that high doses of zinc can be unsafe. Does this mean that the experts are being inconsistent? Not at all. The effects of zinc supplements are moderated by the level of zinc and protein already in the body. For individuals with a zinc deficiency, supplements may improve immune function, but for individuals with adequate zinc levels, supplements can have deleterious effects on the immune system. Supplemental zinc, for example, can block the absorption of iron – another mineral that affects general health and the immune system. Sometimes, excess amounts of one micronutrient can create a cascade of other problems. In a separate study, arginine (an amino acid) was shown to reduce infectious risk by stimulating the immune system. However, among people living with autoimmune conditions, immune-enhancing elements may actually intensify health problems.

How Do I Know If I Am Getting the Right Balance of Micronutrients?

One way is to work with a qualified health professional such as a gastroenterologist and registered dietitian (RD). By studying the blood and taking a close look at dietary intake, they can determine what nutrients are lacking, adequate or in excess. If there is a deficiency, the next step is to determine why it is occurring. Finally, the physician can figure out how to safely remedy any deficiencies. Nutrition is very complex, but counseling by an experienced RD and contacting a professional association with a disease-specific support staff enable individuals to get proper dietary counseling that meets their unique needs.

Why Does Protein Matter?

Protein contains essential amino acids that are the building blocks of life and regulate almost every

biochemical reaction in the body. Protein is therefore necessary for growth, healing and immune responses. For a healthy adult, about 0.8 grams of protein per kilogram (kg) per day is recommended. For example: a 150 lb. person / 2.2 lbs. (to convert lbs. to kg) = 68 kg person x 0.8 grams/kg = 55 grams of protein per day for a 150 lb. person. Infants and children need anywhere from 1 to 2 grams per kilogram of body weight per day depending on their age. However, illnesses change the equation substantially. During a serious infection or injury, most of the individual's initial weight loss comes from internal protein stores (e.g., muscle), so they may need two times the amount of protein – whether or not they are overweight.

Even before weight loss occurs, nutrition problems may show up as protein loss. Blood level of albumin is an easy measure of internal protein stores and level of nutrition risk. Some micronutrients, such as zinc, get to where they are needed in the body by taking a ride with the protein albumin. As a result, low albumin may cause a person to experience micronutrient deficits, which compromise immunity. Pre-albumin is a more timely and sensitive indicator of malnutrition. Always consult with a professional when estimating protein needs, because high protein diets are contraindicated in some medical conditions.

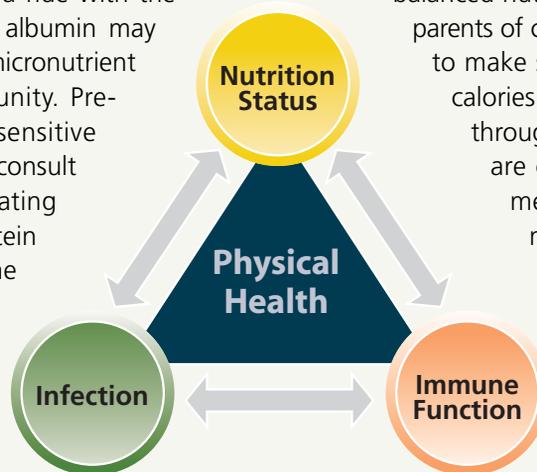
Does Fat Affect the Immune System?

Because a high-fat diet decreases immune function, there may be benefits to a diet that includes low to moderate amounts of fat (20-35 percent of the diet). Yet recent evidence suggests that, in addition to the total amount of fat, health and immune function are greatly affected by the type of fats that people consume. For example, overemphasizing certain fats in the diet has been shown to alter the composition of immune cells. A high ratio of omega-6 (e.g., oils from corn, soybeans, safflower or cottonseed) to omega-3 fatty acids (e.g., fatty acids from salmon, herring, tuna, flaxseed, walnuts, canola oil or tofu) can contribute to inflammation. In contrast, marine animal oil or omega-3s (rich in docosahexaenoate [DHA] and eicosapentaenoate [EPA]) have been shown to influence lymphocyte proliferation and reduce some forms of inflammation. In some cases, this improves immune function, but the safety profile is unknown for many supplements and there are

still unanswered questions about the appropriate dosage. Until the benefits are better defined, it is advisable to work with a physician when any type of supplement is used. Current recommendations on dietary fats for the general public include a reduced intake of saturated fat and trans fatty acids, and balanced intake of poly- and monounsaturated fatty acids. Until more is known, a sensible approach includes a variety and balance of fats from different food sources.

Does Body Weight Matter?

Maintaining a proper weight affects a person's ability to survive acute illness. Regardless of the presence or absence of infectious complications, sickness and death are more likely to occur when weight loss is uncontrolled. Because sick days make it particularly challenging to achieve a balanced diet, it is important to get proper and balanced nutrition whenever possible. For example, parents of children with immune deficiencies know to make sure that their children get enough calories when they are healthy to carry them through the periods when they are ill. These are children who cannot afford to skip meals, so kids who will eat only pizza may get to eat a lot of pizza.



Are There Antibodies in Breast Milk?

Yes. Public health experts recommend that mothers nurse, pump and store milk as long as they are able and it is safe to do so. It

is now recognized that toddlers continue to benefit from breast milk because certain antibodies in the milk become more concentrated over time. Children with immune deficiencies and allergies are especially likely to benefit from extended nursing. In some cases, however, certain protein intolerances may preclude a mother from nursing her baby.

In sum, because nutrition status affects immune functioning in many ways, optimizing dietary intake may be one way to improve quality of life. Always consult with an experienced physician and nutrition expert for dietary recommendations that meet your individual health needs. ■

This material is provided for informational purposes only. It is not intended as a substitute for medical advice or care offered by physicians.

Port Access for IVIG: Another Option

By Dan Bennett

This is the third and final story in a series featuring the three methods of immune globulin administration. IVIG administration was detailed in the February-March issue while subcutaneous administration (SCIG) was profiled in the April-May issue. In this series, patients and physicians with varying experiences and opinions share their viewpoints with readers. No particular method of administration is recommended in this series, as patients should consult their physicians to determine what is best for their individual needs.

Administration of immune globulin using the port method may not be the most popular of the three infusion choices, but for some people, ports work best.

Although Kelliann Conner and one of her two daughters recently switched to subcutaneous administration (SCIG or SubQ), for the two years before that, ports—the long-term placement of an infusion entry point—served the family's needs.

"Our oldest daughter and I were having a lot of negative side effects from intravenous infusion," said Conner, a Washington state resident. "Ports were the best choice for us at the time."

Two years ago, Conner's youngest daughter, Abigail, then 5, was diagnosed with an immune deficiency. Older sister Madison, then 7, was diagnosed soon after, and then Conner herself was diagnosed, at age 37.

"I was very sick as a child but nobody could figure out why," Conner said. "I went through 47 hospitalizations before I was in high school. Doctors tended to blame my parents for me getting sick all the time. Then my daughters were getting sick, and just like with my parents, doctors kind of blamed me in different ways for their illnesses. It took an allergist to deliver the proper diagnosis; then we were all diagnosed."

"The port was much easier. She didn't feel anything. She could play video games and do other things with her hands."

A few tries with IVIG administration convinced Conner to try ports.

"We put Abigail on a port pretty much right away, because an IV can be very traumatic at age 5," Conner said. "The port was much easier. She didn't feel anything. She could play video games and do other things with her hands. When her older sister was diagnosed, she wanted to stay with IV at first, but when she saw how her sister liked the port, she asked to change, also."

Conner experienced problems with IVIG, which ultimately led her to opt for a port.

"It took the nurse 14 tries to get the IV in me, and I knew I needed to try a port," Conner said. "I already

had knowledge of ports, because I had used a port earlier when I had a bone infection. It wasn't that difficult of a decision for me."

Conner, now 39, and Madison, now 9, recently switched to subcutaneous infusion.

"Our levels stay more consistent with subcutaneous," Conner said. "We went to a conference in June 2005 [where they learned about SCIG], then decided to try subcutaneous that October. But Abigail has kept her port. When she goes to the hospital for anything, she often needs an IV. If she didn't have the port, there would be a problem. It's a safety and security thing for her, and for things like blood draws, it's easier. She really wants to hang on to the port, because it's a lot less stressful for her when she goes to the hospital."

Dr. Richard Schiff, Global Medical Director for Immune Therapy at Baxter Bioscience, and a leading authority on IG infusions, says multiple factors play a role in deciding what administration method to use.

"Certainly the use of the port has its critics, and certainly the port has proven beneficial to many patients," Schiff said. "This is another example of how the many varying needs of immune globulin patients help dictate a method."

Problems with veins are the most common reasons patients use ports: Ports go directly into a central vein, allowing easier access. However, the central vein connection poses a greater risk of life-threatening infection than a peripheral needle stick,

so ports require extra attention to proper technique. Schiff recommends careful consideration and frequent consultation with doctors.

"The needs of the patients can change, and the best choice for administration can change along with that," Schiff said. "This is absolutely an ongoing process."

Rachel Kraft, a 16-year-old Kent, Wash., resident, began IG treatments at age 3.

"We began with an IV, but there were difficulties," said Rachel's mother, Lorri Kraft. "We put a port in and that method has been wonderful for Rachel. She is on her second port now."

Lorri Kraft keeps on top of new developments, and has listened carefully to discussion on the SCIG administration method.

"We decided against it, because for one thing, we have established a routine that doesn't take as long for the infusion as SubQ would take," Kraft said. "We were having problems with the portacath four months ago, and our doctor suggested we switch to subcutaneous, but we told her we didn't agree. I made appointments with different surgeons, and we figured out that the needle wasn't reaching the port. Nobody had

thought of that, so that shows the importance of consulting different types of doctors. That said, we are very happy with our primary doctor, because she will back me up once I make a decision. I'm my daughter's advocate, and she respects that."

In the long term, Kraft says, there will be more challenges.

"Rachel is two years away from college, so when she goes, she will need to have a plan in place for her treatments," Kraft said. "One of her options is staying close to home for college, where she can continue her treatments at the same hospital. But certainly there are issues that will come up that someday might make subcutaneous a practical option."

Kris McFalls, an IG specialist for a homecare company, is familiar with all three methods of immune globulin administration, having two sons with PIDD who've tried them all.

"The pros of using a port include easy access, meaning there is no need to dig around for a vein," said McFalls. "They can be used for blood draws and are easy for family members to use. In some cases a port can eliminate the need for a nurse—patients can learn to use it themselves."

The negatives of ports, McFalls

says, include the fact it takes a surgical procedure to install and remove the port, and the resulting scar can be large.

"And not all medical professionals can access them, meaning there could be a wait for someone on the IV team with experience in accessing ports," McFalls said. "Also, whoever accesses ports needs to be trained in and carry out very good sterile techniques. This is not just a clean procedure, it is a sterile procedure. Also, if the port gets hit in sports, it can hurt. It really should be protected with padding if playing contact sports. Not all doctors will support the desire for a port, especially with the availability of SCIG; some doctors will never support the desire for a port."

Despite frequent talk in the IG community that other options may be more viable, some patients and their families continue to opt for the port method.

"We were amazed at how many people are anti-port," Kelliann Conner said. "They talked about things like the risk of infection. But every family and every person is different. Watching my kids suffer every few weeks was worse than the infusion itself. The benefits outweighed the risks for us." ■



Cleansing the port site, using sterile technique, is essential before accessing the port.

Recap of Port Pros and Cons

Advantages

- Easy venous access
- Immediate accessibility for blood draws
- Simple for family members to help
- Shorter administration time

Disadvantages

- Involves a surgical procedure
- May result in scarring
- Poses a risk of infection
- Requires sterile technique
- Necessitates frequent consultation with doctors

My Very Own Three-Ring Circus

By Cheryl Haggard



"Are you going to be OK?" my friendly pharmacist asked, while ringing up my kids' pureed antibiotics. It must have been the look on my face that caused her concern or perhaps it was the glares we were getting from the line behind us.

"Yeah, I'll survive. Things could be worse," I replied, tapping into my "I'm just trying to find a barbecue in Hades" optimism.

"Cheryl," she said, "no offense, but nothing looks worse than you guys right now." Then we laughed—hard—because if we hadn't laughed, we surely would have cried.

Between Caleb's peripherally inserted central catheter line, snugly wrapped on his chubby, 3-year-old forearm,

and 1-year-old Molly's sinus discharge coating the shopping cart with green slime, our trip to the supermarket pharmacy was par for the course. It was kindergartner Calvin's countenance that horrified the local patronage: The 27 stitches carefully placed in his back the night before were oozing stuff through his muscle shirt, and he kept walking into displays as his right eye was patched to strengthen his lazy left eye. I was secretly hoping that someone would call the authorities on me at that moment as I am convinced that our appearance resembled something out of "The Thing" or "Rosemary's Baby."

Two teenage girls gawking at us got the brunt end of my frustration as it slipped from my lips: "We're a walking billboard for birth control, aren't we?!" I felt

badly for being snippy, because I probably scared away two potentially good babysitters.

Since a paddy wagon did not greet me on the way out of the store, I decided to take my carnival sideshow home.

"How was your day, Hon?" my husband Mark mumbled as he shoveled mashed potatoes into his mouth. A faraway look on my face must have tipped him off to how my journey to the pharmacy went.

"I need to go on a milk run," I desperately responded.

"I need to go on a milk run" is our secret little code for "Cheryl is about to blow and, even though we have three gallons of 2%, a trip to the store is in order."

Clutching the keys to our trusty SUV and blowing kisses to my precious carnies, I headed toward paradise: the card aisle at the dollar store.

I find refreshment and people of like mind in the card aisle. There are common understandings and unwritten rules in our club: condemnation of recklessly laughing at colorful pieces of paper is not allowed; one must not judge the harried person snickering at cardstock; and there is no shame in leg-crossing to prevent wetting thyself if one becomes overwhelmed with guffawing.

Feeling a sense of relief after an hour of card-gazing, I made my way to the milk case and eventually the checkout counter.

As I approached our humble family vehicle, a sickening feeling invaded my serenity. I didn't want to go back to the circus I called home. Funny, as a kid I dreamed about running away from home to join Barnum and Bailey. At this moment, as a parent raising kids with a primary immune deficiency disease, all I wanted to do was run away from the big top. I was fed up with choking antibiotics down Molly, forcing Caleb to sit still for his daily IV treatments and convincing Calvin to ignore the teasing and accept that patching his eye would help him see better. I'd had it with sinus washes, steroids and heparin flushes. I was done with trying to keep the piles of EOBs (explanation of benefits), co-payments and appeals to the insurance company organized. Reluctantly, I snapped myself into my safety belt and pondered, Where is that blessed paddy wagon?



As I pulled out onto the road that takes me home, the flash of red lights and the eerie sounds of sirens pierced my thoughts. An accident involving a car and a bicyclist had happened seconds before I arrived at the intersection. The cyclist was still in the street, and the car that appeared to have bumped into him was parked in the turn lane.

The battle for my thoughts began as I watched the brave man lying on the hot pavement. Miraculously, he was not hurt too badly – he was smiling at his attendants.

"Boy, do I envy him!" I uttered under my breath. "Imagine all the attention he's going to get! People are going to ask him if he is OK, with true sincerity and sympathy. They are going to lay him on a sterile gurney adorned with sparkling-clean sheets that he didn't have to wash. He's going to get a refreshing drink of cold water without asking, and they are going to make every attempt to make him comfortable. After his nice ride in the air-conditioned ambulance, absent of three screaming kids in the back seat, he will probably get to stay in the hospital overnight, where they will treat him like a king and watch every move he makes, assuring he gets proper rest! He might even get eight straight, uninterrupted hours of sleep! Sheesh! The last time I got a good nap was when I was sedated for a colonoscopy!"

The unrelenting, jealous thoughts kept peppering at me. "I betcha he gets breakfast in bed and no one is going to fight him for the remote. He will probably get to watch "Judge Judy" and "Regis and Kelly" without feeling guilty that little eyes might be watching! And to top the whole thing off, someone is going to pick him up from the hospital instead of the other way around!"

Then it occurred to me that, for a moment, I actually wanted to be that poor sap!

Returning to the Suburban Big Top that is my home, I realized that trading places with the unfortunate bicyclist was neither realistic nor as adventuresome as my own three-ring circus. Our family understands that IV pole races can become heated and that used syringes make remarkable squirt guns. I'm confident that I know more about the human immune system than the average Joe, and nothing beats butterfly kisses from a toddler who has tubes hanging out of her fragile body.

Even though I wouldn't wish primary immune deficiency disease on my worst enemy, I have to admit that the kids' condition has made us savor dinner a little longer, caused the sun to shine brighter, and yes, even made the circus clowns just a bit sillier. ■

Intravenous Immune Globulin Research

From IG Living

The effect of intravenous immune globulin (IVIG) therapy can be nothing short of miraculous in a wide range of disorders. While the most common use of IVIG therapy is in treating primary immune deficiencies, its efficacy in numerous other disorders is well documented. In fact, it is estimated that for every FDA-approved indication, there are more than 10 non-FDA-approved indications. In certain neurological and dermatological disorders it is considered a first-line agent. In other areas, such as renal transplant and cardiology, it has established itself as an integral part of the patient's therapy. Every month there are more than a dozen new articles published relative to IVIG therapy.

Complicating the expansion of use of IVIG therapy into many of these newly discovered areas are the current short supply of product and continual reimbursement challenges. While costs to manufacture IVIG continue to rise, reimbursement in many cases is below the clinician's acquisition cost of the product. Efforts to convince government and private insurance payers that higher reimbursement is necessary have been, for the most part, unsuccessful.

Despite the supply and reimbursement concerns, a variety of research relating to IVIG is being performed. While the majority of the currently ongoing studies are being conducted by clinical researchers, several of the manufacturers of IVIG are performing studies of their products in specific areas such as neurological disorders. An example of this is the use of IVIG in chronic inflammatory demyelinating polyneuropathy (CIDP). Although not an FDA-approved indication, CIDP

is an established and reimbursed indication. Because it is not FDA approved, IVIG sales representatives are prohibited from calling on neurologists. Once a manufacturer has an FDA-approved indication in neurology, the sales force from that manufacturer will then be able to call on neurologists. This affords them an advantage over other manufacturers as only their sales force will be able to discuss these indications with those specialists. Considering that the largest per gram use of IVIG is in the specialty of neurology, it makes sense for manufacturers to pursue these studies. Additionally, some manufacturers of IVIG that are not currently available in the United States are performing the necessary licensing studies in primary immune deficiency disease (PID) in order to market their products in the U.S. market.

Other ongoing studies cover Phase I through Phase IV studies. These typically look at the efficacy of IVIG in non-FDA-approved indications. Sometimes this is in a new area where IVIG has not been extensively trialed, and, in other cases, it is to better determine the proper dosing to achieve maximum efficacy. The best resource for these studies is the website www.clinicaltrials.gov.

Another resource for studies is the individual patient's specialists. They may be aware of other studies that are in the planning stages. Also, some of the manufacturers of IVIG have funds available for small private studies if they show merit. Clinical researchers can apply for funding of these studies in their areas of expertise.

To stay abreast of immune globulin clinical trials, become familiar with the website www.clinicaltrials.gov, and visit it regularly. ■

Table summarizes some current ongoing studies.

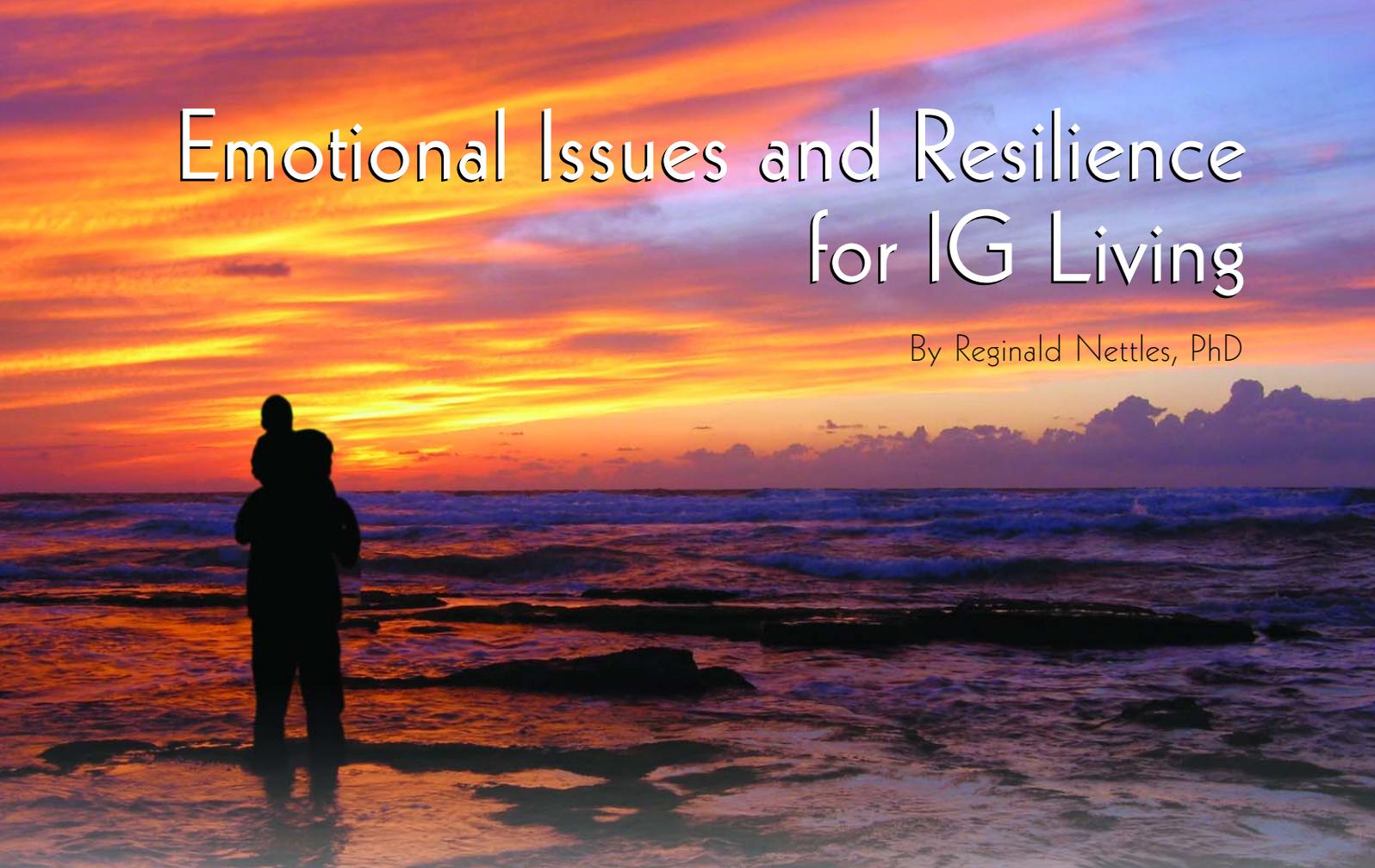
For studies that have a National Clinical Trial (NCT) number, more detailed information is available at www.clinicaltrials.gov.

Sponsor	Study Title	Study Design	Phase	Status
Baxter	Conduct Deferred Pediatric Studies Under PREA for the Treatment of Primary Immune Deficiency in Pediatric Patients	Treatment		Application submitted
Talecris	Randomized, Double-Blind, Placebo Controlled Study to Compare the Effects of Different Dose Regimens of IGIV-Chromatography (IGIV-C), 10% Treatment on Relapses in Patients With Relapsing Remitting Multiple Sclerosis	Randomized, Double-Blind, Placebo Controlled Study		Delayed
Talecris	Investigating IGIV-C 10% Given at Different Infusion Rates on Intravascular Hemolysis in Patients With Idiopathic (Immune) Thrombocytopenic Purpura (ITP)	Randomized, Controlled, Open Study		Fulfilled

Sponsor	Study Title	Study Design	Phase	Status
Talecris	Multicenter, Randomized, Double-Blind, Controlled Study to Evaluate the Efficacy and Safety of IGIV-Chromatography (IGIV-C), 10% Compared to Placebo in Patients With Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)	Multicenter, Randomized, Double-Blind, Controlled Study		Pending
Oswaldo Cruz Foundation	Efficacy of High-Dose Intravenous Immune Globulin Therapy for Hyperbilirubinemia Due to Rh Hemolytic Disease NCT00288600	Treatment, Randomized, Double-Blind, Active Control, Single Group Assignment, Efficacy Study	Phase IV	Start 2/06 Expected completion 12/09
National Human Genome Research Institute (NHGRI)	Intravenous Immune Globulin to Treat Hereditary Inclusion Body Myopathy NCT00195637	Treatment, Safety	Phase I	Start 9/05
Children's Oncology Group – National Cancer Institute (NCI)	Cyclophosphamide and Prednisone With and Without Immunoglobulin in Treating Abnormal Muscle Movement in Children With Neuroblastoma NCT00033293	Treatment	Phase II	Start 4/02 (See website for treatment centers)
Emory University – Sanofi-Synthelabo – Center for Disease Control and Prevention	Yellow Fever Virus Vaccine and Immune Globulin Study NCT00254826	Prevention, Randomized, Double-Blind, Placebo Control, Single Group Assignment, Efficacy Study	Phase I	Start 11/05
Arcasoy, Selim, M.D. – Columbia University – Talecris Biotherapeutics	Intravenous Immunoglobulin (IVIg) in Lung Transplantation NCT00115778	Prevention, Randomized, Double-Blind, Placebo Control, Crossover Assignment, Safety/Efficacy Study	Phase II	Start 6/05 Expected Completion 6/07
ZLB Behring	Treatment of Chronic Immune Thrombocytopenic Purpura (ITP) With Intravenous Immunoglobulin IgPro10 NCT00168038	Treatment, Non-Randomized, Open Label, Uncontrolled, Single Group Assignment, Safety/Efficacy Study	Phase III	Start 12/04
University of Pittsburgh – Shadyside Hospital Foundation – Bayer Corporation	IVIg Versus Placebo for the Treatment of Patients With Severe C-Diff NCT00177970	Randomized, Double-Blind, Placebo Control, Single Group Assignment	Phase IV	Start 10/03
National Institutes of Health Clinical Center (CC)	Omr-IgG-am™ for Treating Patients With or at High Risk for West Nile Virus Disease NCT00069316	Treatment, Safety/Efficacy	Phase II	Start 9/03
National Institute of Allergy and Infectious Diseases (NIAID)	IVIg – West Nile Encephalitis: Safety and Efficacy NCT00068055	Treatment, Randomized, Double-Blind, Placebo Control, Parallel Assignment, Safety/Efficacy Study	Phase I (Omr-IgG-am) Phase II (Polygam S/D)	Start 9/03 Expected completion 12/05 (not met) (See website for treatment centers)
Bio Products Laboratory	Efficacy, Safety and Pharmacokinetics of Gammalex in Primary Immunodeficiency Diseases NCT00278954	Treatment, Non-Randomized, Open Label, Uncontrolled, Single Group Assignment, Safety/Efficacy Study	Phase III	Start 1/06 Expected completion 12/07
National Human Genome Research Institute (NHGRI)	Molecular and Clinical Studies of Primary Immunodeficiency Diseases NCT00006319	Natural History	Not specified	Start 9/00
Radboud University	Treatment of Patients With Idiopathic Membranous Nephropathy NCT00135954	Treatment, Randomized, Open Label, Active Control, Parallel Assignment, Safety/Efficacy Study	Phase III	Start 7/97
Swiss Institute for Applied Cancer Research	Antithymocyte Globulin and Cyclosporine Compared With Standard Therapy in Treating Patients With Myelodysplastic Syndrome NCT00004208	Treatment	Phase III	Start 1/00 (Study is being performed in Switzerland only)
National Institute of Allergy and Infectious Diseases (NIAID)	Immune Regulation in Patients With Common Variable Immunodeficiency and Related Syndromes NCT00001244	Natural History	Not specified	Start 9/89

Emotional Issues and Resilience for IG Living

By Reginald Nettles, PhD



“No human problem is more poignant than the distress caused by physical illness. Illness can incapacitate people, damage lifelong values and commitments, destroy social relationships, produce role losses, generate discomfort and pain, result in repeated or continual loss of dignity, force a person to live with debilitating uncertainties, and threaten life itself.”

—R.S. Lazarus

The potential results of illness, coupled with the dynamics of a *chronic* illness, contribute to the emotional impact that is to be reckoned with in successful treatment, self-care and management of the disease for each person affected by it. Coping with these issues takes resilience, the capacity to bounce back from trauma and adversity. Managing strong feelings and impulses is an important ingredient in resilience. Because the capacity to deal with the strong feelings associated with such severe illness is limited in children, the supportive physical presence of a loving parent can go a long way in bolstering that capacity.

Picture an 8-year-old, riding piggyback on his father's shoulders into the front door of a hospital. Someone tries to strike up a conversation with the pair about the obvious incongruity of the scene.

"What are you doing here?
Oh...he can't be sick; look at those rosy cheeks!"

Observing this interaction in silence from my father's back, while burning up with fever and half delirious, I wasted no energy on a response and merely kept riding. But inside, I was steaming, not only from the fever but also from the ease with which the well-meaning passer-by had misinterpreted our situation and jumped to a completely false impression about my condition.

This long-past vignette illustrates the physical and emotional impact of acute illness and the social context of denial, minimization and trivialization of physical distress. It was not my first bout of pneumonia, and having already lived through poliomyelitis and osteomyelitis, I was no stranger to illness and hospitalization, but this event stands out in my memory as my first brush with people's misinterpreting apparent signs of acute illness. Given their capacity to ignore the obvious, it is not surprising that people have difficulty understanding and responding appropriately to what may *not* be obvious. The denial, misunderstanding, discrimination and poor treatment that may result are among the emotional hurdles in the lives of people with chronic illnesses in general and primary immune deficiency disease (PIDD) in particular.

My father's shoulders, in the midst of what was a very distressing situation for a feverish 8-year-old, are a metaphor for the emotional support and physical safety that can be so

necessary when facing the trauma of a debilitating and life-threatening illness. For the young child, the nurturing support of parents and other caregivers is an essential ingredient in the mastery of the psychological trauma of severe illness.

Helping Children Cope

Parents can help the young child cope with chronic illness by providing information at the level that the child can understand. Allowing the child to ask questions and to express emotions freely can also help. Young children may experience being taken to a hospital or forced to stay in bed as punishment. It is important to help children know that they have not done anything wrong and that they are not being bad when they are sick. Allowing children to talk and cry about what is bothering them, and to express their sadness and fear, is important. Though this can be painful for parents to endure, it is important to be there for the child. Many children will want to draw pictures and tell stories about their illnesses as a way of mastering the trauma. The importance of the physical presence of a loving and supportive parent in alleviating the distress of a sick child cannot be overstated.

Coping at Any Age

At any age, learning to deal with the emotional, social and interpersonal aspects of living with chronic illness is second only to physical survival and good physical healthcare. The ability to face the strong emotions involved is essential to being able to bounce back from these adversities. An important first step is accepting the feelings that come along with being sick. ➤

Challenges of PIDD

PIDD is a general term referring to the more than 100 disorders resulting from one or more congenital defects in the immune system. These genetically based, incurable, chronic illnesses are most often associated with frequent episodes of acute infections or other illnesses. The overall physical health impact of PIDD can vary widely, depending on the specific disorder, from frequent infections to chronic fatigue and general malaise to physical disability. For many people with PIDD there are no outward signs of chronic illness. For others, depending on the specific disorder, disability may occur, resulting in the need to use assistive devices.

If you have been challenged by medical personnel when you explain that you have—or your child has—a congenital immunological disorder, you may be aware of how quickly any description of PIDD can be heard by others as AIDS—and how daunting such misinterpretation of your illness can be. Having to explain the need for a longer-than-usual course of antibiotic therapy during a sinus infection can be similarly challenging, unless, and until, you have a solid healthcare team in place with a primary care physician who fully understands the unique protocols required for effective treatment of acute illnesses in a PIDD patient.

Unfortunately, being told that the illness is "all in your head" is also a common experience on the journey to accurate diagnosis and treatment of PIDD.

Sharing Your Feelings

Having supportive people with whom to share feelings is next. It is important for friends, family, spouses and partners to know how to accept the feelings of an ill loved one or a caregiver with empathy and support. Too often well-meaning individuals rush to problem-solve when another person feels distressed. This, among adults, is typically counter-productive. What we need most when distressed, beyond having our physical care needs met, is a

warm and responsive person to provide sufficient emotional support for the emotional “holding” we need in times of distress.

Having access to peers or support groups of individuals who share similar experiences can be an effective tool for managing emotional reactions to distress for adults and children. People who know firsthand what one is going through can often provide necessary support. In addition, because of shared experiences, they may be able to provide useful information

that may not be available from others. Typically, support groups combine emotional expression and support with problem-solving and shared common experiences. Virtual support networks, in the form of message boards or discussion forums may also be useful, depending on one's individual needs.

Changes in Coping Ability

The cumulative impact of the stressors associated with a chronic disease can be overwhelming. It is important for individuals and their

Online Peer Support Links

Guillain-Barré Syndrome

GBS & CIDP Discussion Forum—UK
Bulletin Board—For Ireland and England
<http://www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi>

GBS Support group—UK
Chat room—requires registration
<http://www.jsmarcussen.com/gbs/uk/chat.htm>

GBS Foundation Discussion Forums
www.guillain-barre.com/forums

Yahoo Support Group
Discussion Board
http://health.groups.yahoo.com/group/GBS_CIDP/

PIDD

Chat with parents of children affected by PIDD
<http://health.groups.yahoo.com/group/PedPID/>

Chat with peers with PIDD
<http://health.groups.yahoo.com/group/PIDsupport/>

Immune Deficiency Foundation Forum
www.primaryimmune.org/forums/forum_intro.htm

Jeffery Modell Foundation
Message Board
www.jmfworld.com

Neuropathy

MSN Support Group
Discussion Board
<http://groups.msn.com/PNPARTNERS>

The Neuropathy Association Bulletin Board
www.neuropathy.org

Yahoo Neuropathy Support Group
Discussion Board
<http://health.groups.yahoo.com/group/neuropathy/>

Yahoo Support Group—Australia
Discussion Board
<http://au.groups.yahoo.com/group/LifeWithPN/>

Myositis

Juvenile Myositis Family Support Network
http://www.curejm.com/family_support/index.htm

Myositis Association Community Forum
www.myositis.org

Myositis Support Group UK
<http://www.myositis.org.uk/>

Yahoo Myositis Support Group
Discussion Board
<http://health.groups.yahoo.com/group/OurMyositis/>

caregivers to be aware of emotional distress and changes in ability to cope that may signal the onset of excessive anxiety and depression. Sadness and grief are normal reactions to loss, severe illness and disability. When reactions become extreme and normal sadness turns to depression and loss of ability to function continues for an extended period of time, psychotherapy by a qualified psychologist or other mental health provider is recommended. Typical warning signs of depression and anxiety include sleep disturbance (too much or too little), appetite disturbance, feeling sad and blue more often than not, loss of interest in pleasurable activities, indecisiveness, feelings of worthlessness, addictive behaviors, and recurring thoughts of death or suicide. In some cases, medication may be needed in addition to psychotherapy. A therapist who has done a thorough assessment can assist you in determining whether evaluation for medication is indicated.

Relationships in Distress

Given the profound impact of a seriously ill child on marriage and family, couples need to be aware of signs of relationship distress that call for intervention. Couples in distress tend to wait far too long before seeking help. If your child or partner has a chronic disease, seeking assistance early when you recognize difficulty is advisable. Irritability, emotional distance and increases in fighting are warning signs of problems. Often during times of distress, couples find themselves locked in negative interaction cycles. Severe illness is one of the greatest challenges an intimate relationship can endure. Many marriages fall apart when either a child or a partner develops a chronic, life-threatening or disabling condition. Learning how to weather the storm

and solidify the vitally important emotional bond between you and your loved ones may be crucial when faced with this challenge.

Coaching and Other Assistance

For individuals who are doing well in resolving the emotional storms of chronic disease, but still feel the need for assistance in moving forward and formulating new goals for their lives, virtual coaching may be appropriate. Coaching differs from psychotherapy in that it is not a mental health service and focuses on moving forward rather than attempting to resolve emotional issues. Coaching is primarily individual, can be done by telephone, and may include virtual support groups, lectures and discussions.

While much has changed since the 1950s when I was a small child, stigma, bias, and misunderstanding continue to affect the lives of those with PIDD and other chronic and rare diseases. Fortunately, medical research and advances in treatment have come a long way in the past 25 years. Thanks to the advocacy of numerous individuals and organizations, and with medical research, many people who would not have lived into adulthood with PIDD can now hope to live relatively normal lives. Resources and programs developed by these organizations provide education and training to physicians and other healthcare providers. A wealth of



supportive information is now available to assist individuals and families in gaining access to state-of-the-art medical care and appropriate accommodations in work and school settings.

Chronic illness is not a mental health problem, but the trauma of severe illness requires emotional support. Getting the support you or your child needs and knowing when to get treatment for the emotional symptoms that may result is an important part of your resilience tool kit.

If you seek psychotherapy, peer support, coaching or a combination of resources, it is recommended that you work with individuals who understand chronic illness in general and PIDD in particular. ■

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My Date With IVIG

By Ever Fecske

On February 27, 2005, I became an active member of the primary immune deficiency disease (PIDD) community. I have CVID, or common variable immune deficiency. It's funny that I remember the exact date: It was the day everything finally came into focus, the day I got the answers I had been looking for, for so long. I was 20 years old and about to discover and adopt a new way of living. It was time I acknowledged the fact that I was in a relationship with a very needy immune system.

At first, my doctors just threw medical terms at me. I would sound them out and write them down and then try to find them on the Internet later. We were having communication issues, my immune system and I, but like most relationships, if it's worth it, you work through it.

What my doctors were telling me was that the reason I was sick all the time with bronchitis and sinus infections and a sore throat was because I am deficient in my immunoglobulins. My what?!? Gosh, maybe my girlfriends were wrong about this one.

Immunoglobulins are basically the part of the blood that operates the immune system. Oh...right...of course. Actually, I still wasn't really getting it, at least not completely; it was a "just smile and nod" situation.

I could tell that there were going to be tough times ahead for me and my immune system, and, although it had only been a matter of weeks, we definitely needed a mediator. So the two of us were sent to an immunologist, and it was there that we began to understand each other. My immunologist suggested intravenous immune globulin



(IVIG) as a treatment. He explained that I would be receiving infusion therapy every four weeks to replace the immunoglobulins missing in my body. The treatment would prevent me from getting sick as often.

Sounded good to me. I desperately wanted to start feeling better. My immune system was holding me back from doing the things I loved. Because of my ongoing infections, I was not able to sing or perform. Singing is my passion and it was being compromised. If IVIG was going to get me back on the stage and put a microphone back in my hand, then I was all for it.

My first date with my IVIG treatment was March 16, 2005. I arrived at the clinic around 8:30 a.m.—way too early in my opinion—and waited for my medication to be “mixed.” Who knew it had to be mixed? Apparently some IVIG comes in powder form and the pharmacist has to dissolve the medication in sterile water in order to give it intravenously. Just a little something I learned. Another thing, it takes two hours to dissolve and is good for only 24

hours. Pretty high maintenance, but I like to think I'm worth it. Ha ha.

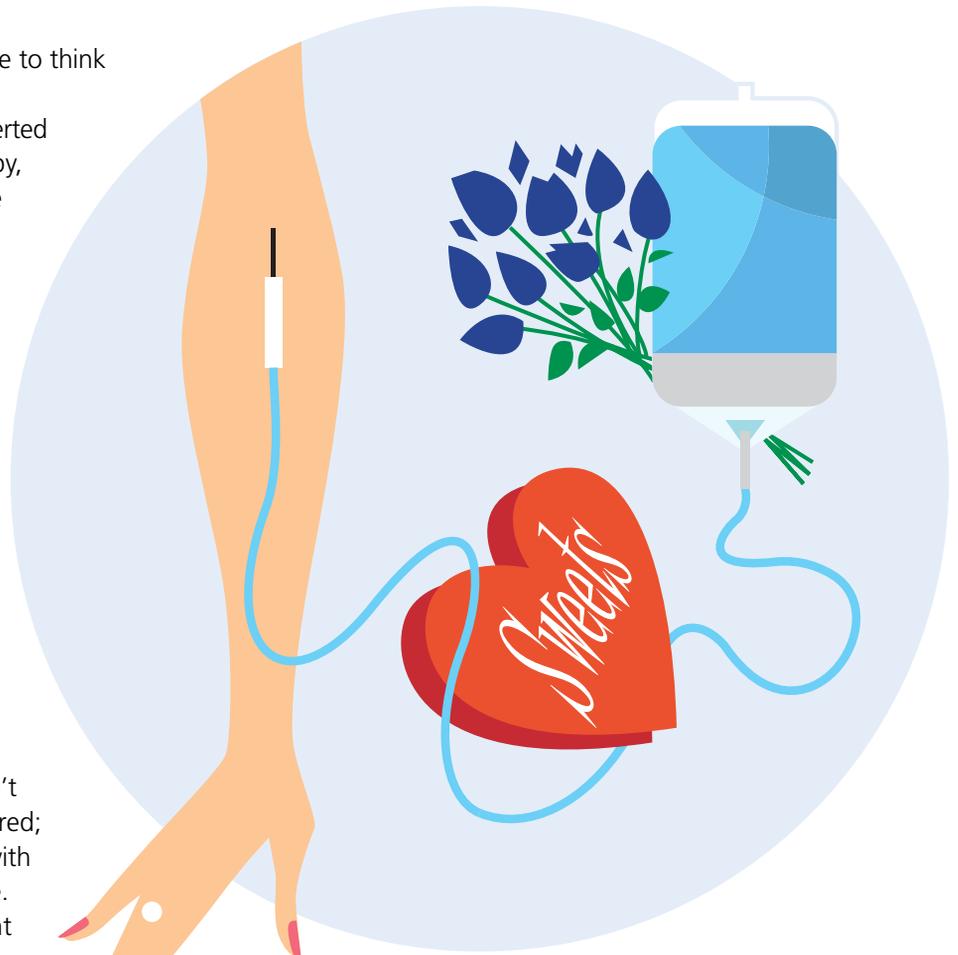
Anyway, around 11 a.m. the nurse inserted the IV. I don't want to seem like a baby, but it hurt! Although, when it came right down to it, I was definitely willing to deal with a little pain.

The treatment took four hours. Four hours of just sitting there. I knew the next time I would bring a book. There is nothing like a romance novel to spice up the long, sterile hours in the infusion center. Who knows, maybe a little romance will rekindle my immune system's sudden lack of interest.

When it was all over, I felt pretty good—a little shaky and weak—but good. I went home, had dinner and hit the sack early. Around 11:30 p.m., I woke up with the shakes and shivers and severe joint pain. I didn't know what was happening. I felt scared; I was lost in my body and overcome with new sensations that I just couldn't place. The pain would jump around from joint to joint like it had a mind of its own. I've heard of tantrums, but this was out of control! My immune system obviously wanted something, but waking me out of a dead sleep was not the way to get it!

Thankfully I live with my family, so my mom came into my room to comfort me. I was finding it extremely hard to relax. She finally decided that I was having a reaction to my treatment and gave me something for the pain and to help me sleep.

Looking back, it was a rough first date with IVIG, and to make it worse the sparks absolutely did not fly. Some people I have talked to have no reaction at all; I guess it all depends. Since then, my treatments have gotten a lot better and smoother. I suppose my immune system and I are now more of a team. Now I call the infusion clinic the day before my treatment so they have my medicine ready for me when I get there. My immunologist prescribed some pre-meds so I don't have the nasty reaction. Also, I get treatment every two weeks instead of every four. I think of it as my own custom-made formula to help me reach the healthiest me possible.



It's scary to be faced with such a challenge at a young age. I feel guilty at times, because my brain tells me to get up and go—the world is mine!—but my body doesn't respond. My brain is a Mecca of energy, full of thoughts and ideas desperate to perform and impress, but my body is tired and just needs to rest. I get frustrated with myself and my situation, and I ask why? But deep down I know why. Thanks to my CVID, my strength and being positive, I am learning more than I ever imagined. It's something that can't be taught in school. It is through my experiences that I am learning about people and behavior, and about fear and love. It is through all of this that I have learned the will to survive.

As for my immune system, our relationship is growing every day. The two of us have made a lot of compromises, and we have learned to work together. And from experience, he knows that if he ever tries to pull a fast one on me, I'm much faster! ■

Jacob's Return to Health

Words cannot fully express my joy at our son's return to health after he began SCIG therapy for his immune deficiency—or my gratitude for the help we received in finding a treatment that brought him back to us.

Jacob has made a miraculous recovery from a series of illnesses that plagued his young life. It seems our delightful 3-year-old has been sick since he was born. The past two years have been the worst—a rocky, very scary road for us, trying to find a way to help him feel better. He was in the hospital five times in seven months, as he seemed to catch every bug under the sun. One of Jacob's mysterious symptoms was intermittent mouth sores. Acyclovir didn't help him and seemed to add to his neutropenia.

My mommy instinct told me something was very wrong when time and time again physicians reported his labs were abnormal, but they didn't know what it all meant. In my search for

answers, I was fortunate to become involved with a group of parents on the Internet who steered me to the Immune Deficiency Foundation (IDF). While attending an IDF conference, I met the staff from a homecare company, and they provided invaluable information and support.

Our doctors told us we should just "wait and see." Meanwhile, Jacob's stamina noticeably declined, and 30 minutes of playing outside exhausted him. He would tell me, "I tired, Mommy" or "My legs out of batteries."

Early in September, we realized Jacob had mouth sores again—two large ones. His labs revealed he was mildly neutropenic. His appetite disappeared, and he started to eat less and less. By mid-October, he had a three-week episode of constant mouth sores. Still, physicians weren't sure what to do, but one recommended IVIG treatment. Because Jacob experienced serious side effects when he received one dose of IVIG the previous year, I was hesitant, especially since I had learned of other options at the IDF conference.

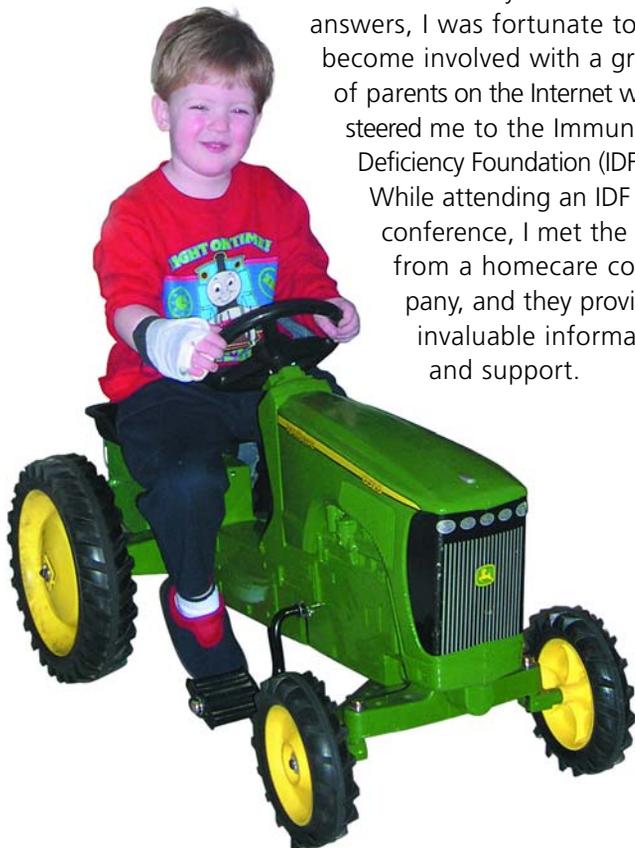
Jacob's downhill spiral continued. His mouth appeared to improve, at least where we could see, but he quit eating and drinking, telling us he "already ate" when, indeed, he hadn't. His stay in the hospital for dehydration really scared me and that's when I contacted the homecare company for information to help support my suggestion to my pediatrician of SCIG therapy, rather than IVIG.

I am so thankful for the homecare company's help in getting Jacob started on SCIG. On the second day in the hospital after his infusions, both my pediatrician and hematologist noticed he looked better. Soon, he started to eat and drink and actually tell us he was hungry.

Now, he has pink cheeks and the dark circles under his eyes have disappeared. His energy level has been restored, and he asked to stay at his big sister's second basketball game one night. He is sleeping soundly, his appetite has returned and his mood is better. We just had our three-week check after starting SCIG, and our pediatrician said that Jacob looks great and he's cautiously optimistic that this will be the answer for our boy.

"Thank you" just doesn't seem like enough for the miracle of getting our son and our life back. We feel absolutely blessed! ■

—Linda, Jacob's mother



Get the Most From Your Doctor Visit

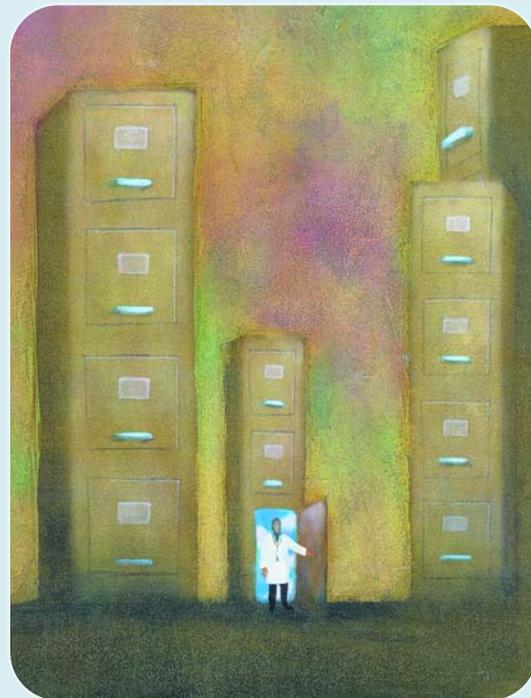
From IG Living

Managing a chronic disease can be challenging, but there are those who've been at it for a while who have some great tips to make your path a little easier. Some of the best suggestions we've received target one of the more important aspects of managing your disease—appointments with your healthcare providers.

Your appointments should be informative and fruitful, and with a little nudge they can be. So, who is the best person to provide that nudge? You!

How to Prepare for Your Appointment

- You are your own best advocate. This is your job, not your physician's. You know best what ails you and what questions and concerns you have about your treatment. Take yourself seriously—be your own ardent advocate at every appointment.
- Keep a diary of your health—and illnesses—and bring it with you to every appointment.
- The average time a doctor spends with a patient is less than 15 minutes. Take a little time before your appointment to make sure you know what you want to achieve during it. Go into the appointment knowing what you want to bring home from it.
- Make a list of your questions and concerns, and remember to bring them with you—along with a pen or pencil so you can make note of your physician's responses.
- Make a list of all the symptoms and problems that you are experiencing so you can review them with your doctor.
- Make a list of all medications you are currently taking, including over-the-counter products, herbal supplements, etc., and share the list with your physician.
- If your doctor ordered any labs or tests at your last appointment, be sure to have them done well in advance of the next appointment so the results will be available to discuss.
- Bring your own medical records file with you—particularly if you see other healthcare providers. This may prove a good resource during the appointment.
- Bring the names and contact information for any other practitioners you are seeing.
- Bring your infusion log to review with your doctor, and your insurance information for proper billing.
- If you have a co-payment, bring your checkbook.
- Be early to the appointment. Many offices have the nurse do a triage prior to your seeing the doctor, so you may end up having more time with the doctor, if she or he is not already running late.
- If you want to discuss a possible new treatment with your physician, bring articles or other information about it to back up the discussion.



Improving Access to Your Physician

- Try to get the first appointment of the day or the first one right after lunch. This reduces the amount of time you have to sit in the waiting room, being exposed to possible infections.
- Ask your doctor how to reach her or him in an emergency, and carry the information with you in your wallet.
- Make friends with the staff member in your physician's office who works most closely with him or her. This person can get you extra time with your doctor if you need it.
- If you need your physician to sign a form or write a letter for school, work or disability, ask well in advance of your deadline.
- Consider buying a fax machine: It goes directly to your doctor as is, unlike phone messages (the meaning of which can be lost in translation), and whatever you fax is put in your chart. ➤

Get the Most From Your Doctor Visit

...continued

Questions to Ask About New Prescriptions

- Is the medication available in a generic form?
- Does the medication have side effects? If so, what are they? What should I do to treat them?
- What should I do if I miss a dose?
- Am I currently taking anything that could interact with my new medication?
- Do any other prescribed or over-the-counter medications interact with my medication(s)?
- Will I need any lab tests to monitor how this medication affects me?
- How long after starting the medication should I notice a change or improvement in my condition?

Try the Buddy System

- It's a good idea to bring someone to the appointment with you. He or she can listen and take notes to help you remember what the doctor has said. Even your own list of questions can fail you if you don't feel well or the questions are not addressed in the order you've written them. Take advantage of your support system, and bring a buddy with you.
- Perhaps most important, remember that your body needs the same commitment you would give anyone else you love. If you are not receiving the information or care you need, be firmly and politely persistent—maybe try a little humor—but don't give up. You wouldn't be passive if your child or mate were ill, so take an active role in pursuing the quality of healthcare you deserve—the best there is! 📌

If you have tips you'd like to share with our readers, please email them to editor@igliving.com or call 800-843-7477 x1143.

Many thanks to Patient Services Incorporated, from whose publication this article was adapted.

So What Exactly Is CIDP?

By Barbara Katzman

It was early morning and Greta jumped out of bed as she did each day. This day, however, she knew immediately that something wasn't right. Her legs seemed weak. She assumed she had slept on them in a contorted way and proceeded to go through the rituals of her day. Weeks passed and the weakness took over insidiously until she experienced numbness in her hands and feet and a weakness throughout her body. She found it difficult to walk. She had been to her internist three weeks earlier, but he had dismissed her symptoms as a temporary nuisance. Now, as she sat in his office once again, he was making an appointment for her to see a neurologist. What was happening?

Chronic inflammatory demyelinating polyneuropathy (CIDP) is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms. It is caused by damage to the myelin, the covering that protects nerves. Generally, the weakness occurs over a period of two or more months. CIDP can happen at any age and affects both genders and all ethnicities.

Greta entered the neurologist's office not knowing what to expect. The physician tested her muscle strength and reflexes and ordered several diagnostic tests.

To diagnose CIDP, a neurologist will test the strength of individual muscles and the patient's reflexes in the weak extremities. Specifically, the knee and ankle jerk reflexes are nonexistent in CIDP patients. Diagnostic tests generally include an electrical test, called a nerve conduction velocity-electromyography

study. This test would show a slowed or blocked electrical signal. A spinal tap will analyze cerebrospinal fluid to determine if there is an elevated protein level and little or no white blood cells, typical of a CIDP patient.

"OK." Greta thought. "Now that I have been diagnosed with CIDP, what's next? Will I recover? Are there any treatment options? And, how did I get it?"

Current theory holds that the body's immune system, which normally protects the body, perceives the myelin as foreign and, instead, attacks it. Just what starts this process is still unclear. The good news is that about 80 percent of CIDP patients respond well to some type of therapy. Several treatment options are generally used. Steroids, such as prednisone, are often beneficial, easily administered and inexpensive, but they can be associated with serious side effects. Two other approaches have been found to be effective for many patients: high-dose intravenous immune globulin, blood

proteins derived from the plasma of healthy volunteers; and plasma exchange, or plasmapheresis, the process of removing the patient's blood, separating the blood cells from the plasma, and returning the blood cells to the patient. These therapies may have to be repeated on a regular basis. Because weakness is the predominant symptom, many CIDP patients benefit from physical and occupational therapy.

Greta never heard of CIDP. She hoped for a support group that could supply her with additional information.

The Guillain-Barré Syndrome/CIDP Foundation International is a nonprofit organization founded in 1980 to help patients with Guillain-Barré syndrome (GBS) or CIDP and their families. The organization now has more than 160 chapters and affiliated organizations worldwide, with a mailing list that exceeds 20,000 people. The mission of the organization is to improve the quality of life for patients with GBS or CIDP and their families by providing support, research sponsorship, and lay and professional educational programs worldwide.

The organization is proud of its prestigious Medical Advisory Board, which includes some of the world's leading experts on GBS and CIDP. These neurologists are available to consult with physicians around the world. For more information, visit www.gbsfi.com or call 610-667-0131. In the meantime, know that there is research ongoing to unlock the mysteries of CIDP. ■



Barbara Katzman is Associate Director of the Guillain-Barré Syndrome/CIDP Foundation International.

Mother Dolores

Contemplating Peripheral Neuropathy

By Dick Sheridan

"I'm never without pain," says Mother Dolores Hart, OSB, sitting at a long table in an alcove off the main waiting room at her neurologist's crowded office overlooking Madison Avenue. "It's like two hot iron rods are wrapped around my feet."

Mother Dolores, 67, suffers from a condition called inflammatory sensory neuropathy. It started with a botched root canal in 1997 that triggered an autoimmune reaction against her peripheral nerves. After making the rounds of multiple medical specialties, all with varying opinions about how to relieve her pain—from steroids to surgery—a process that may be all too familiar to many neuropathy sufferers, she finally arrived at her current physician.

Despite her acknowledgment of pain, Mother Dolores' expression is calm and carefree. The skin of her face is smooth and pink. Only her eyes, which are big and blue, occasionally betray her discomfort. Her hands rest easily on the tabletop in front of her. A needle is stuck into a large vein on the back of one hand and is attached to a long tube that runs up to a large plastic intravenous bag hanging from an aluminum tree behind her chair.

"It's not excruciating pain," adds Mother Dolores, ignoring the apparatus that looms over her shoulder. "It's just the kind that keeps you from thinking about anything else."

The plastic bag holds 30 grams of immune globulin in solution. It will take more than two hours for all the contents to drip down into Mother Dolores' vein. The immune globulin treatment, repeated every two weeks, is meant to prevent the inflammation that invades the nerves in her arms and legs and to keep it from spreading up along her neural pathway to other parts of her body, explains Mother Dolores' physician, Norman Latov, MD, PhD. Latov is professor of neurology and neuroscience and director of the Peripheral Neuropathy Clinical and Research Center at the Weill Medical College of Cornell University.

"Gamma globulin is frequently prescribed in small amounts to fight off infections, and in larger doses to prevent autoimmunity," he explains. "Mother Dolores was severely disabled and confined to a wheelchair before the



treatments, but with them, she is now able to function almost normally."

There are other patients attached to similar aluminum trees sitting in nooks and crannies scattered throughout the office. Most of them appear to be middle-aged to elderly. The thing that sets Mother Dolores apart from all the others is the fact that she is wearing the black-and-white habit that marks her as a nun.

Mother Dolores is a member of the Roman Catholic Order of Saint Benedict, one of the oldest, strictest and most revered bodies in the Church. The order got its start back in the mid-sixth century, when Benedict established the so-called Benedictine Rule to govern the operation of his own abbey at Monte Cassino in Italy. The Benedictine Rule proved popular and the order proliferated rapidly across northern and western Europe. By the seventh century, the Benedictine Rule had been extended to houses of nuns as well.

As a member of this contemplative order, Mother Dolores lives a largely peaceful and secluded life devoted to prayer and manual labor, with about 40 of her sisters who live together on the 400 acres of farm fields and woodland in western Connecticut that comprise the Abbey of Regina Laudis. The name is Latin and translates as "Queen of Praise." The abbey, which was established in 1947, lies nestled in the hilly terrain on the outskirts of the town of Bethlehem in Litchfield County, roughly a two-hour drive north of Manhattan.

"Our main duty is to recite the Divine Office," she explains, referring to the so-called Liturgy of the Hours. The liturgy consists of a series of eight sets of psalms and prayers that form the Catholic Church's main ritual of prayer other than the Mass. They must be recited or sung at specified times of the day, starting with "Matins," at 1:50 a.m. The other daily prayers are "Lauds" (sung at dawn), "Prime" (6 a.m.), "Terce" (9 a.m.), "Sext" (noon), "None" (3 p.m.), "Vespers" (dusk) and "Compline" (before retiring for the night).

"We follow the strict traditional way of our order and chant the Divine Office in Latin," says Mother Dolores. The nuns of Regina Laudis have recorded a CD of their Gregorian chanting, or plainsong, which they sell through their website and to visitors to the abbey.

When not engaged in prayer, the nuns of Regina Laudis work to maintain the abbey and themselves. They grow

much of their own food and raise cattle, swine and other livestock. Mother Dolores ran the abbey's carpenter shop for a while. She is now prioress of the abbey, which is the second highest ranking nun in Regina Laudis after the abbess.

People who knew Mother Dolores growing up probably never imagined her wearing the habit of a contemplative nun nor wielding a hammer and saw in an abbey carpenter shop. Not unless doing so was written for her in a Hollywood movie script. Because, until 1963, when she suddenly disappeared behind abbey walls, Mother Dolores was one of Hollywood's biggest, most beautiful and most successful stars. It was something she almost had seemed destined for from birth.

Mother Dolores Hart was born Dolores Hicks on October 20, 1938, in Chicago. She was the only child of an Irish father, Hollywood character actor Bert Hicks, and an Italian mother. "My parents were a real-life Romeo-and-Juliet couple," says Mother Dolores. "They were very young when they got married, and their parents were very much against the marriage."

The marriage ended in divorce, and at age 3, Dolores went to live with her grandparents. "My grandfather was a movie theater projectionist," she says. "He used to take me to work and had me sit up in the booth with him. I used to look out at the big screen for my daddy to appear. That's how I came to dream of becoming an actor."

Little Dolores made so many trips back and forth between Chicago and Hollywood by the age of 10 that "I started to call both places home," she recalls. Dolores finally moved to Southern California at age 11, after her mother remarried. "I became a real Hollywood brat," she says. "I spent a lot of time when I was young with my cousins, the Lanza girls. Their father was actor and singer Mario Lanza. He was my dad's old Army buddy."

Dolores' first taste of acting came at the age of 9, when she won a bit part playing a child in the 1947 release of "Forever Amber." Ten years later she skipped out on her ➤



freshman drama class final exam at Marymount College in Westwood to audition for Hollywood producer Hal Wallis. Her teacher gave her an F, but Dolores (now named Hart) had gained a seven-year contract.

She appeared in a series of films in quick succession: "Loving You," starring Elvis Presley, and "Wild Is the Wind" in 1957; "Lonelyhearts" and "King Creole," her second appearance opposite Presley, in 1958; "The Plunderers" and the teen classic "Where the Boys Are" in 1960; "Francis of Assisi" and "Sail a Crooked Ship" in 1961; "Lisa," her personal favorite, in 1962; and finally "Come Fly With Me" in 1963.

However, Dolores' talents were not limited to the big screen. In 1959, she appeared on Broadway with Cyril Ritchard, who also directed, and Charlie Ruggles in "The Pleasure of His Company." For her work onstage she received a Theatre World Award and a Tony Award nomination as Best Featured Actress. She also appeared on network television, accepting roles in popular series of the time such as "Alfred Hitchcock Presents," "Schlitz Playhouse of Stars," "The June Allison Show," "Playhouse 90," and "The Virginian." By 1963, Dolores was at the top of her profession. She had been Hollywood's top-grossing actress the previous year. Her agent, Harry Bernsen, boasted that she was going to be "the next Grace Kelly."

Dolores' personal life also seemed to be going swimmingly. Though the movie-town rumor mill had linked her off-screen with two-time co-star Elvis Presley, a story that she always denied, she had in actuality maintained a long-term relationship with wealthy Los Angeles businessman Don Robinson. He even proposed marriage.

But Dolores Hart had a secret desire. As a child living in her grandmother's house she had observed the values of love of God and love of peace by which the older woman lived, and had heard these values reflected in the religious instruction that her classmates were given as they studied to receive their First Holy Communion. "I wanted to be



like them," Mother Dolores says now. "I wanted to receive my First Holy Communion."

Her grandmother had given her permission, and little Dolores had become a Catholic, a faith she would hold to throughout her life.

Harry Bernsen inadvertently rekindled Dolores' love of the simple faith that she had experienced in her grand-

mother's home by introducing her to the Abbey of Regina Laudis.

"He sent me up there as a kind of retreat where I could rest up between projects," Mother Dolores says.

After several visits to the bucolic abbey and plenty of time to think about her future, she told Don Robinson she could not marry him. Then she left Hollywood and all its promise and joined the nuns of Regina Laudis.

Over the 43 years that have passed since she first entered the cloistered life, Mother Dolores has only occasionally left the confines of the abbey. One of the remaining ties she maintains with her previous life—besides unbroken friendships with Don Robinson and with Maria Cooper Janis, the daughter of Hollywood legend Gary Cooper—is the Screen Actors Guild membership card that she holds onto so that each year she can cast her ballot for the Oscars.

Now she has traveled to Washington, D.C., to testify before the House Labor Health and Human Services Committee, as national spokesperson for The Neuropathy Association, to urge lawmakers to increase support for neuropathy research. She has also made a trip back to Hollywood to take part in a fundraiser.

Regardless of her years out of the spotlight, Mother Dolores says, "I am still a public person. I receive a hundred letters a month.

"I have an obligation to do whatever I can so that the will of the Lord is done, to do whatever he wants," she says. "If I can promote some good for somebody, I will. ... A community at prayer has as much power as a community in Washington," she says. ■

Charlie's Book

By Jeff Siegel

At the time, Dayna Fladhammer didn't think much about what she was doing. It just seemed like the sensible thing to do, so she did it.

"I was a teacher before I became a mom, and I learned the value of using books to prepare kids for different life events," says Fladhammer, a Las Vegas resident whose three children have been diagnosed with primary immune deficiency disease (PIDD). "When Charlie was to become a big brother, I bought a book about it; the same thing for potty training. I looked everywhere for something that was appropriate for starting IVIG (intravenous immune globulin therapy), but I

could only find things about staying overnight in the hospital, which he didn't need, or getting your tonsils out, which again, didn't fit. So, I just decided to write it myself."

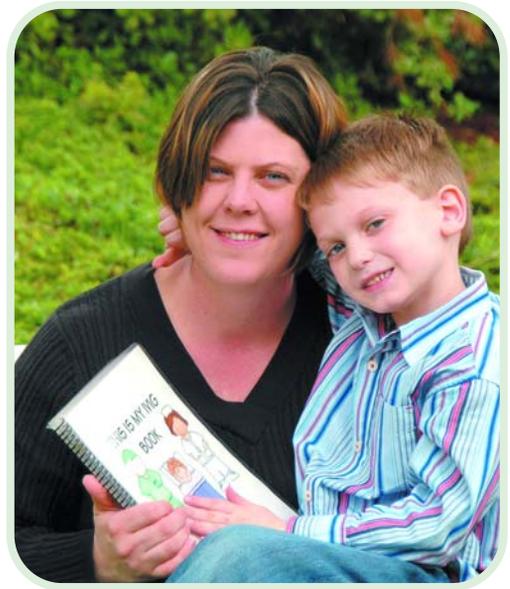
Hence her book, called simply enough, "This Is My IVIG Book," was published by Baxter Healthcare Corporation in April, and is being distributed with a template to help PIDD families put together their own personalized books. "This Is My IVIG Book" explains what it's like to go through an infusion—from the perspective of then 3-year-old Charlie. In this, it might be the first of its kind in the world.

"Why did we do it? That's a hard question to answer, but only because it seems so totally obvious," says David Bond, Baxter's senior product manager for antibody therapy. "Why wouldn't we want to do it? It's all about helping people return to a normal life, and that's what we do as a company."

From the Beginning

So how did Fladhammer hook up with Baxter, a nearly \$10 billion company that does business all over the world? Almost by accident, actually.

"It never even occurred to me that someone would want to publish it," says

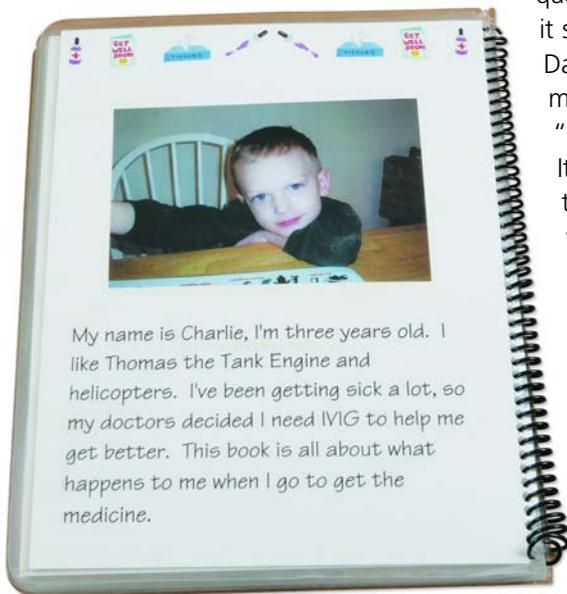


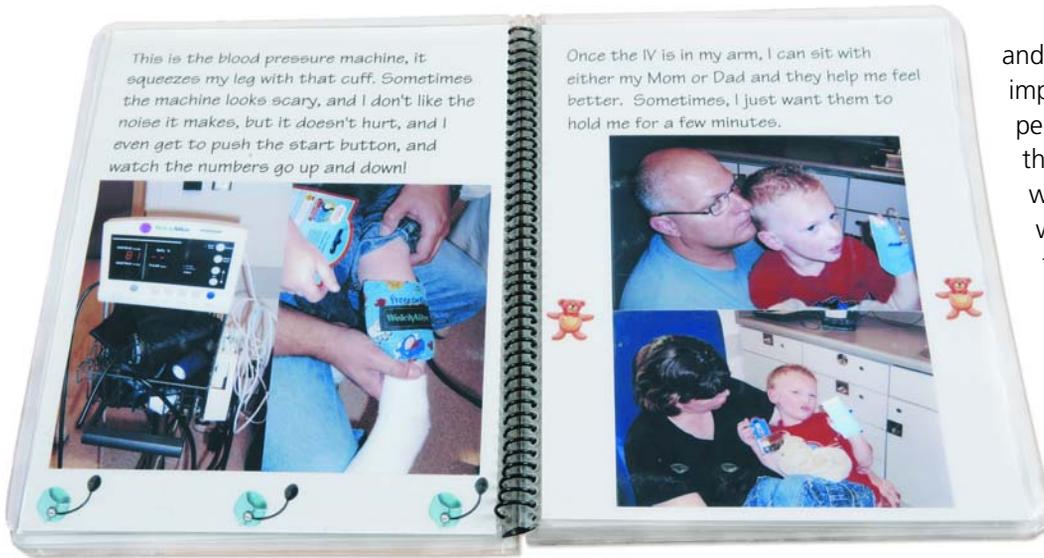
Fladhammer. "My husband was the first one who suggested it, and I blew him off, to be honest with you."

But that was before she and husband Brian saw Bond at a couple of conferences. At the first conference, the subject never came up, although Fladhammer says she was thinking then about writing a second, more general book about dealing with PIDD and infusions, with less of a focus on Charlie. At the second conference, late last year, Fladhammer did show Bond the book, and he was quite interested in it.

"It wasn't so much the book that intrigued me," says Bond, "but what the book was trying to do. It showed not just what Charlie was going through, but it demystified the process for everyone. That's one of the things that's so great about the template. You can do your own book, and then it's not so scary, and everyone can get a handle on it."

Says Fladhammer: "David got how important this could be for kids to see other kids in the same situation, but he also got that the process of doing this—that Charlie and I did this together—was what was ➤





and wherefore of an infusion, as important as they are. There's a personal angle to the narrative that helps explain why Bond wanted to include the template with the book, to allow every family facing the same fears and uncertainties to have something to make their task a little easier.

"It was a labor of love for us, and I knew that including Charlie was an important part of the process," says Fladhammer. "So, for me, it's a time I'll always

treasure—he was scared, and I could do something to help him, which hadn't always been the case before. For multiple blood draws, he was scared, and I had to stand there, while they held him down, screaming and begging me not to let them do it to him. All I could do was hold his hand, and be there.

"I was determined to make IVIG a positive for him, to give it a purpose—to let him know, even at 3, why he was doing it, and what it would do for him. I knew all of that would help him be comfortable. It gave him such a base knowledge, and a little bit of control in what must have been scary to a 3-year-old. I think when you're creating something out of love, it's not the difficulty you think about, at least for me. I focused in on what I thought it would give Charlie."

Helping Others

And others, as well. "I wish there had been something like this when my kids started their infusions," says Kris McFalls, whose two sons, ages 21 and 19, started their treatments more than 15 years ago. "I can remember calling around and asking people if there was anything like this, and there wasn't."

The great need, says McFalls,

important. The template was David's idea from the start, and I just loved it."

At its most basic, "This Is My IVIG Book" is a collection of pictures and text, almost a scrapbook of Charlie's immune globulin infusion experiences. The Fladhammers brought a camera to Charlie's first infusion and took a lot of pictures, especially of things Charlie was afraid of, such as the blood pressure monitor. They also posed a lot of questions to the nurses, asking them to explain procedures and processes. Then, when the family got home that night, they re-enacted Charlie's day, but with a couple of key differences. Charlie was the nurse and Brian was the patient. The goal? To get Charlie's thoughts and transfer them to text in the book.

Keeping Track

"I was stunned by how much he remembered, and his impressions of the day," says Fladhammer. "I got right to work narrating it with him. The most difficult part was trying to get it done fast enough, and trying to put all the pieces together, getting the stickers, the lamination, and printing it all out. It was time-consuming."

But also worthwhile, because there is a lot more to Charlie's book than just the basic whys



Charlie shares his book with David.

is for something “to take out the emotion and the drama that kids go through. You go in there with all sorts of qualms, and the kids are nervous. And if they’re nervous, it’s that much harder to find the veins.”

So far, and even though the book has yet to reach much of the audience it is intended for (it is estimated that there are 50,000 people diagnosed with PIDD in the United States, so the audience is limited), McFalls’ sort of enthusiasm has been the general reaction:

- One of the Fladhammers’ pediatricians, Lorraine Stern, was so impressed she wrote about it in her column in Women’s Day magazine.
- Charlie’s brother and sister, who have been diagnosed with PIDD and receive infusions, are also impressed. Kate, 3, will get her own book later this year and Tommy, 2, likes to look at the pictures and yell, “IG!”
- Several of Charlie’s friends, classmates and other children with PIDD have done their own books or used Charlie’s, and the results have been gratifying for Fladhammer.

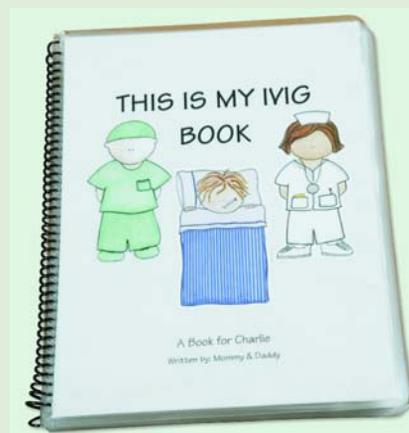
Charlie read the book to one little girl, and then lent it to her to take to her first infusion. “I was lucky enough to be able to attend her first infusion and see her look at the pictures, and tell her mom what was coming next,” says Fladhammer, and you can almost see the smile on her face over the phone as she tells this story.

Because, in the end, that’s what this is all about.

“When I wrote the book, I expected the benefit to be just to Charlie, to reduce his anxiety about this treatment, but it’s done so much more,” says Dayna. “His friends get what he does, so do his extended family and teachers, and I love how it’s allowed Charlie to have control, and share his experiences as he has gotten older. I really hope seeing this book will help other parents feel motivated to do it for their own kids. I also hope that the template will make it less intimidating for people to take this on. I’d love to create a website for kids to upload copies of their books for others to read.”

Which, who knows, may well be next. Bond realizes what his company has discovered. “There aren’t many people like Dayna,” he says. “She has three kids with PIDD, and that sets her apart. But she is intellectually and emotionally engaged and involved, an extraordinary individual. She is not just a great mom, but a role model for how to deal with this.”

And, apparently, a pretty good writer. ■



How to Obtain “This Is My IVIG Book”

Dayna Fladhammer’s “This Is My IVIG Book” and its companion book template are not hard to get. Just go to the website www.immunedisease.com, choose the United States or Europe, and then click on the appropriate link. Fill out the form, and that’s it. There’s no charge, no need to pay, nothing at all.

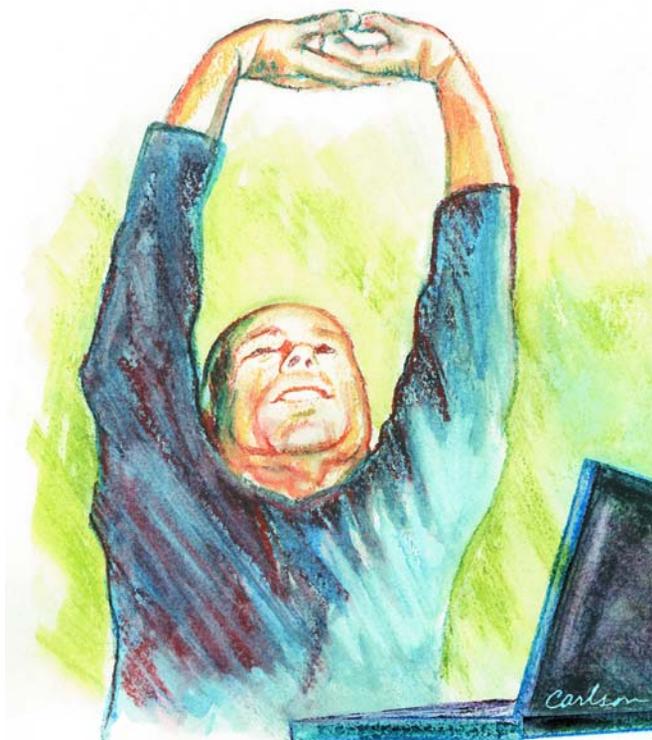
“I’m thrilled out of my mind that Baxter wants to publish the book, but it’s not just the book. To me, the best part is the commitment to making a template for other parents to follow, to make the process easy,” says Fladhammer. “Honestly, prior to meeting Baxter employees who work on IVIG, I thought of Baxter as a company, not people who care about the community they serve.”

The website also offers a variety of PIDD-related material, including links to research and support groups, as well as a new patient starter kit, a game for patients to play, instructions on how to keep an infusion log, and a flip chart detailing the immune system.

— Jeff Siegel

To Exercere* or Not to Exercere; That Is the Question

By Carol K. Miletti



OK, OK, I didn't want to use the English word for fear of scaring you away, but wouldn't it be terrific if we could be in better health without having to exercise?

Guess what? You can—by being dedicated to moving!

To start, let's divide ourselves into three categories:

- 1 The long-distance runner, cyclist, six-pack abs group—you can stop reading now; you don't need this advice!
- 2 The person who feels good but not great most days, has fluctuating energy levels, and has an optimistic attitude—at least most days.
- 3 The person who feels as though getting out of bed or making it from one room to the next is totally exhausting—and, by the way, thinks this article stinks!

So, let's focus on groups 2 and 3 and see how we can get into better condition and thus better health through "movement."

But first, confession time! I used to be in group 1. I majored in health and physical education in college, and,

in the past, I've been extremely active, including hiking in the mountains, biking, swimming, yoga, ad nauseam. Why am I telling you all of this? Because that was yesterday, and yesterday is gone—life before PIDD.

So, I now fall into group 2, and, although I sometimes take one step forward and two backward, there are good reasons for incorporating movement into our daily lives: to strengthen the heart muscle; alert the mind; increase self-esteem; reduce stress, tension and anxiety; increase energy level; and help with weight control. But what does this mean for those of us who just don't feel up to the task?

It's a vicious circle: We don't feel like moving, but it is movement that will actually help us to feel better. "Long periods of inactivity in anyone can lead to weakness, stiffness, fatigue, poor appetite, high blood pressure, obesity, osteoporosis, constipation and increased sensitivity to pain, anxiety and depression" according to "Living a Healthy Life With Chronic Illness" by Lorig and Sobel, Laurent and Gonzelez. These symptoms sure sound familiar, don't they? But according to the Mayo Clinic, "because of illness, activities that once were easy now require extra effort because we have less energy and our endurance and activity levels are limited."

How can you incorporate some type of movement into your life? First of all, make sure it's OK with your doctor. Then, identify what you need to do while also making sure to conserve those short energy supplies. Next, be sure to balance periods of movement with rest, and just start moving!

It helps to embrace a "can-do" attitude. Use "mindful meditation and think about the activities you used to do or the ones you now want to do, and practice them in your mind first, and then actually perform them," says Candy Swanson. Swanson is a personal trainer who works with many chronically ill and challenged clients at The Marsh, A Center for Balance and Fitness in Minnetonka, Minn. Candy believes that when you wake up, you should start by stretching your arms and legs before you even get out of bed. She also believes in setting goals.

Now, there's a good idea: goal setting. Just focus on short-term goals to begin.

They are much easier to achieve...

...Today, I'm going to spend some time stretching.

...Tomorrow, I will try to do the same, and, if I'm up to it, I just might take a walk, a short walk down my street.

That doesn't sound too difficult, does it? In Lori Hartwell's "Chronically Happy," she recommends that on your very worst days, the bad days we all have, that taking a walk—movement—can help to repair your health.

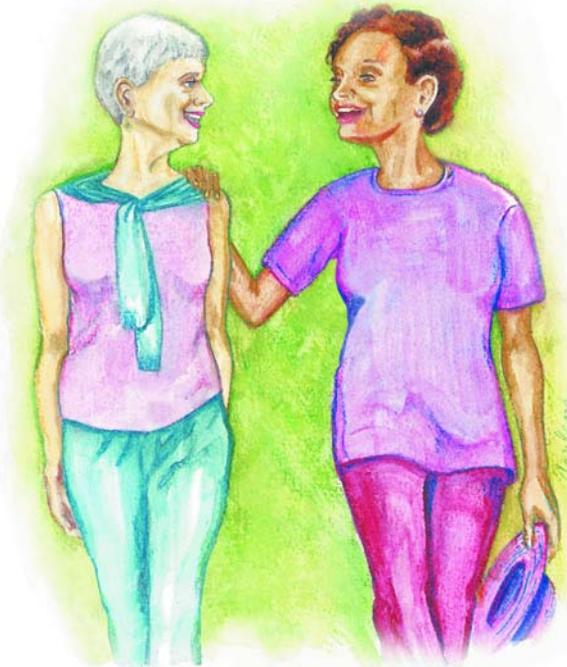
The truth is, small, short bouts of movement—a 10-minute walk, using the stairs in your own home five times a day, housework, gardening, running errands—all work toward reducing the levels of unhealthy fats in your blood more than longer exercise sessions do.

Wow! That's good news, too. This is starting to look easier and easier to achieve. Just remember that you know your body better than anyone else does. Only you know your limitations, and you also know what your potential goals can be.

However, make sure you have a Plan B. Expect that you're going to meet obstacles along the way. Don't overexert, and always make sure you are entertained while you move or you will stop the activity. Believe that what you want to do is possible, and you can meet your expectations.

So, now that you've learned how easy it is to incorporate movement into your life, what will you do about it?

I can share with you what I do. When I am in the most pain, I move the most. I go up and down the stairs



in my home repeatedly on days I'm homebound. When I'm up to it, I walk, a nice and easy stroll. And now, another confession. On the evening of the 2006 Super Bowl, I was experiencing horrendous pain in my sacroiliac joint. I tried hot baths, pain pills, yoga, but nothing was working. Then Mick Jagger came on during halftime, and I danced with him—move for move—and that's a lot of hip motion. Guess what? I felt so much better afterward!

Was it the movement, the music, the attitude? Probably all of the above.

So, groups 2 and 3, start your engines! You don't want to end up like Mark Twain, who said, "Every time I feel the urge to exercise, I lie down until it goes away."

I've spent so long sitting to write this, I need to plug in my iPod and dance! 🎵

Carol Miletti can be contacted at editor@igliving.com.

*Latin for "exercise," compliments of Emily Ernst, this issue's profile PIDD patient and Latin Club member.

From Carol to the Yahoo PIDD members who posted on this topic:

Beth: Keep on trying—even if you go for a walk and it tires you out—take the next few days to recover.

Graham: Keep on walking. And, I don't know if there is any medical proof that IgG keeps you young-looking.

Julie: Hope you're on the way back to the Julie you used to be, but remember the Julie you are now—the one who is working at it and trying so hard—is just perfect.

Donna: Keep trying to walk, whenever you feel up to it. Like I said, one step forward, two steps backward. It's still movement.

Ambre: Parking far away and walking counts. Just do it every chance you get.

Loyd: While mental exercise is certainly admirable, as is the job you do teaching school, I don't think 16-ounce curls count. Try something with more movement.

Penny: Yes, exercise can be a four-letter word. It's great that you are still playing tennis. Don't compare yourself to anyone but yourself. Take it easy and keep moving.

Laurel: Hanging out in the pool with your friends and swimming, moving and talking is what it's all about—moving and having fun!

Some Easy Ways to Start Moving from Julie Hassell, Physical Therapist

Bed stretches: Stretch arms and legs; rotate them; do leg lifts; take full, expansive breaths, the kind that expand your belly and rib cage.

Warm shower stretches: Stand under the shower, and stretch and stretch (until the hot water runs out!).

Chair exercises: Just go through your own range of motion, moving your arms and legs as far as you comfortably can several times, and add a few more every week.

Remember to always start easy and work up to your own capabilities.

Everyone Has a Story and This Is Emily's



By Carol K. Miletti

"Sometimes I feel like I'm running around so much, I don't even have time to think," says Emily Ernst, a 14-year-old high school sophomore, living in Alexandria, Ky. Emily has the outward appearance of health and vitality, and the beauty of youth. Her school activities include skiing, bowling and swimming, for her athletic endeavors; and Latin Club, choir and the school newspaper, for her cerebral side. All the while, she maintains a high level of academic achievement. But Emily's life wasn't always this active.

"I'd like more people to be aware of SCIG because you can do so much more with it—you're not limited at all—you have freedom!"

Emily was born with a type of primary immune deficiency disease (PID) that took more than five agonizing years, three pediatricians and total tenacity on the part of her mom, Carol Ernst, to be properly diagnosed. By the time Emily was 1, she had already had multiple upper respiratory illnesses and pneumonias. She was sick all the time, and yet a doctor actually suggested to Carol that she was the one who needed to see a doctor, a psychiatrist!

Luckily for Emily, her mom is a nurse, and Carol knew for a fact that something serious was going on with her daughter. So they kept forging ahead until they finally got the diagnosis when Emily was 5 1/2 years old: chronic variable immune deficiency (CVID).

Emily began receiving immune globulin intravenously (IVIG) once a month, and stayed with that program until 2002, when she entered a study with Dr. Mel Berger in Cleveland, Ohio. The study included administration of the immune globulin in an entirely different method from what Emily was used to. While Emily admits "I hate infusions," she also does not like change in her life. So at first, she did not like receiving the subcutaneous, or under the skin, infusions of immune globulin (SCIG) that were part of the study—even though it was her mom administering it. But when Emily was 13, she wanted to

attend summer camp. Since it wouldn't look good to have her mom along, Emily had to learn how to do the SCIG infusions herself, and she did!

Now it is apparent that nothing is going to slow down this determined young lady. Emily feels very strongly about SCIG: "I'd like more people to be aware of SCIG because you can do so much more with it—you're not limited at all—you have freedom!" And, looking at Emily's life today, you know how important that freedom is. She would not be able to be involved in all of her current activities if she was still tethered to her IVIG.

This does not mean that Emily's life is perfect. She doesn't dine out with her friends and family, and many of her close friends refer to her as a "germaphobic," because she washes her hands so often and is very diligent about avoiding bugs. But, Emily's family is very supportive, and they do everything they can to help her manage her PIDD. They make sure she has time to rest, and they protect her from those who are sick. Even though CVID can have a genetic link, the rest of Emily's family is healthy, yet they all treat her normally, including her younger sister, who periodically just "totally annoys" Emily, which is the primary role of a younger sibling. Despite that, the sisters are actually very close.

Carol thinks that Emily is "an amazing kid who is well-adjusted, pro-active about her health and extremely poised." She admires her daughter because Emily doesn't dwell on her illness. "This says a lot for how she will handle this disease as an adult. She does what it takes to get through."

The beauty of this story is that Emily sees her mom as her real touchstone. "Mom knows everything," Emily says. They have been through quite a bit together, including numerous visits to doctors, various drug therapies, additional illnesses that have accompanied her CVID, and many ongoing challenges with insurance companies. Through it all, they have become very close, very loving best buddies.

Of all the challenges Emily faces, staying focused when she is tired, paying attention to the fatigue and then taking the time to rest is one challenge that is constant. She is concerned that insurance issues will plague her forever— not what you would expect to hear from a 14-year-old. Emily has her fears, too. She fears that she won't fit in because of her illness and that it will impede her career: She wants to enter the field of classical humanities or biomedical research. Emily's hope is that "someday more doctors will be willing to learn about this disease." And, if Emily has anything to say about it, they will learn plenty.

At 14, Emily is already a very poised, charming and talented young woman. Emily exudes a self-confidence that leaves little doubt she will achieve her goals. ■



Putting the Parenting Spin on IVIG

By Dayna Fladhammer

I admit it, my kids eat Skittles at 9 o'clock in the morning, and they eat sugar all day long too. As long as I'm clearing my conscience, let me add one more horrifying parenting thought. Charlie, the 5-year-old, has a girlfriend, for whom he routinely buys flowers. It's been going on for two years now, this love affair of his, and I condone it... all of it... every three weeks at IVIG. Let me explain. To me, IG for kids should be a special time, kind of like a kiddy spa. It's a time to get rejuvenated, refreshed and ready to take on the world (or at least any bacterial infections that might come their way). My husband and I decided early on we wanted to make IVIG special for the kids, not like any other day.



Thomas Fladhammer, 2, held by his dad, Brian, has his needle inserted to start IVIG.

Consider Bending the Rules on IVIG Day

On the average day, I'd never let my kids eat candy, fruit-flavored or not, at 9 a.m., and likely not at all. However, I've learned to pick my battles, and candy is a small concession I make to help their day be just a little easier. They know, even at 2, 3, and 5, that Mommy won't say no to candy on IVIG day. That doesn't mean all rules should be suspended; remember to keep the ones that are central to your family philosophy. For our family, it's manners. Even when the kids are getting IVIG, we expect them to use please and thank you. We also expect that they will communicate with us in a positive manner. "Get me that" doesn't work whether you're hooked up to an IV or not.

Present IG in a Positive Way

Sometimes, as much as I love IVIG and what it does for our kids, treatment day can be a pain. It takes a lot of time, and frankly, the stress of getting everything ready and making sure everyone's needs are taken care of can be difficult. It's important, however, to put on a happy face for your child. Kids are intuitive and they will likely pick up on your stress. We phrase conversations about treatment in a positive or at least a neutral way. "We're going to IVIG" or "We get to see our favorite nurse today" will get a much more positive response than "We have to go to IVIG."

Establish a Routine

Routines are comforting; that's why we often settle into them. For a child to whom life can be unpredictable and dictated by how their body feels, a routine can be a safety zone. For our family, the routine is fairly simple. Each of our children has an "IVIG-only" blanket. It's kept tucked away to use only on IVIG day. Additionally, we go to the grocery store the morning of IVIG and buy snacks for treatment, which the kids pick out, along with flowers for their favorite nurse. Your family's routine will be different and should be tailored to your child's age; many 16-year-olds

will likely not be as comforted by a blanket as a 7-year-old. However, a word of caution: Do not get so entwined in a routine that deviation becomes devastating. We once ran into a problem when “our” grocery store was closed on infusion day for some sort of internal plumbing problem. Both the older two kids cried and insisted we couldn’t possibly go to IVIG without going to “our” grocery store first. It was a rough IVIG day for the Fladhammer family. Lesson learned. Now we go to a different grocery store every couple of times.

Do Something Special

Taking time to celebrate a successful treatment, or to reduce the stress of an anticipated one, can go a long way, so pick something special to do around treatment time. It could be something as simple as eating breakfast at a special café before treatment or baking cookies to bring to the nurses, but find something you and your child (or children) can do together. I know one family who always brings a craft project to IVIG. They have as much fun trying to figure out something that can be done with only one hand, if need be, as they do working on the actual project itself. It’s yielded interesting results, including painting with their feet!

I’m reminded of a conversation I had with a good friend recently in which we came to the conclusion that PIDD is what our kids have and IVIG is the medicine our kids take,

but neither is who they are. In the time between treatments, make the most of life and enjoy yourself and your family. Take time to stop and enjoy this life—and the benefits of IVIG!

How Some of You Make IVIG Work

“One thing we did turned out to be inexpensive and fun. We bought one of those giant helium-filled butterfly balloons for her very first IVIG at the hospital. Then I found out that they would refill it for a quarter. So when we started home healthcare, I would take it into Safeway the morning of the treatment and get it refilled. She was always thrilled to see her balloon come back to life! We did that probably the whole first year and then forgot about it. I still have the balloon stored as a special memory.”

—Dale, mom to Katy, 20, now off treatment

“Whenever possible, his best friend comes with us to the hospital. This is usually reserved for the summer (we go on Fridays), but those days go so quickly. He loves having Ben at the hospital with us.”

—Sandi, mom to Brian, 13, IVIG

“I have a special backpack with special color books and toys that Jacob can only play with during infusion time... we also try to rent a special movie for him.”

—Linda, mom to Jacob, 3, SCIG

“We have a visiting nurse that comes—same one, from day one, for 5 years. She has become a part of our family. Chris gets picked up early from school that day, we always get lunch for all of us, and he actually enjoys his time with her. She always brings him a surprise (she spoils him, which is just fine), and it’s a nice afternoon, believe it or not. He looks forward to it. He doesn’t dread it at all.”

—Kim, mom to Chris, 9, homecare IVIG



Infusion suite cart with IVIG ancillary supplies.

Let's Talk!

By Shirley German Vulpe, EdD

Let'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.

I met Wynn at a primary immune deficiency disease (PIDD) conference in November 2005, in Carlsbad, Calif. He had an interesting story about obtaining his Social Security and retirement benefits, so I gathered up my courage and called him. I felt very fortunate when he and his wife agreed to share their story with IG Living.

Shirley: Wynn, can you tell me a little bit about your work?

Wynn: I worked as a manager for a national grocery chain. I worked my way up to this position, and was with them for 26 years before I went onto disability, because the work environment was detrimental to my health and I could no longer perform my job.

Shirley: How was it detrimental?

Wynn: I worked with people all of the time. I handled a lot of money, which carries germs. I frequently worked in a cooler where the air is recirculated and going in and out of extreme temperature changes. All of these circumstances were essential parts of the job but contributed to my getting sick so much.

Shirley: What is your history of illness?

Wynn: About six years before I went on disability, I was sick much of the time. I had multiple sinus infections, many of which turned into pneumonia. The doctors also thought I had chronic asthma. I had gastrointestinal problems. I missed work for doctors' visits, sickness and hospitalizations. My ability to perform my work effectively was impaired. My energy was down and my concentration off. I started to make errors that I had never made before. My wife and I were very

concerned about my job security and future retirement. I had to step down from management. This didn't help; I still was sick a lot.

The illnesses also affected my personal life: We have four children—previously I was very active in Boy Scouting. I would come home sick nearly every time I went on a Scout camping trip. So I had to stop.

Shirley: You said "doctors" plural?

Wynn: Yes, everyone thought I needed a different specialist. No one really knew what was causing all this illness. I was seeing up to four specialists and had to tell my story all over again each time—retests and blood work.

Shirley: How did you solve this problem?

Wynn: My wife did! I am lucky! She is hardworking, assertive and my best advocate. I was so sick I had no energy but she was determined! She found out about primary immune deficiency disease (PID) on the computer. The website discussed tests you need to find out if PID is your problem. She told me what tests to ask the doctors to order and why. The doctor ordered lab tests to measure my gammaglobulin levels. My levels were way below the normal levels. I had a diagnosis, and was put on IG infusions. We often joke that I had so few antibodies that I could name them.

Shirley: You were still working, right?

Wynn: Yes, I was diagnosed about 24 years into the 26 years I worked for the store.

Shirley: So what happened next?

Wynn: I kept trying to work, but I was still getting sick a lot even though I was being treated. I have IVIG side effects, like migraines, that made concentration impossible. Ultimately I faced the choice of being terminated or going on disability. I decided on state disability insurance. I discussed this with my doctor and he submitted the necessary paperwork.

Shirley: What about your health insurance?

Wynn: Work paid for a while; then I started paying through COBRA, the extension of group health insurance you get when you quit work. It is expensive but you have to do it.

Shirley: What happened next?

Wynn: My immunologist said I was not going to get any better. I needed the IVIG to live, and I needed to accept the situation, even with the side effects, and go forward. After several

months on state disability, my doctor told me to start filing for permanent disability. He advised me to get a lawyer who specializes in permanent disability, because it can take a long time and require many applications. So we did it. We only had to pay \$75 upfront. There were no other fees. The attorney was paid by Social Security Assistance (SSA). By law, there is a certain percentage that lawyers can take of your settlement.

Shirley: So how did it go?

Wynn: Once again, my wife did a fantastic job! Proper paperwork is the key. She had kept excellent records. She gathered all of the necessary medical records and information. Three physicians signed the required forms. Everything was given to the lawyer, and she submitted the claim.

Shirley: So how long did it take?

Wynn: Four months! I got one year back pay, and was reimbursed for six months of COBRA payments. I get a monthly SSA benefit. My children under 18 also receive monthly benefits from SSA. SSA includes Medicare. In addition, I received my full retirement from work. I was a member of the United Food and Commercial Workers Union and had a pension plan. I had worked for the store for 26 years, but I had to leave on disability at age 43. My retirement is full, as if I was 65, because of the disability status and it includes health insurance coverage.

Shirley: That sounds wonderful. How are you now?

Wynn: I am doing better. I receive my IVIG infusions every three weeks. My wife works and I am Mr. Mom for our four children. I now pace myself and organize my schedule around my IVIG. My children under-

Resources Available for People With Disabilities

Consolidated Omnibus Budget Reconciliation Act (COBRA)
www.dol.gov/esba

Social Security
www.ssa.gov/disability/

California State Disability Insurance (SDI)
www.edd.ca.gov

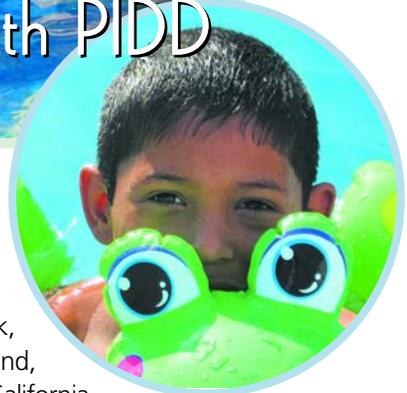
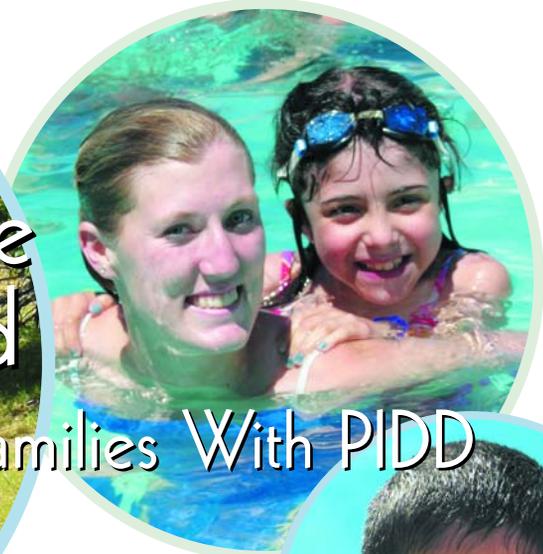
(Please note that each state has a different disability program.)

stand when I need to rest the week before and after my infusions. I do a lot around the house, but I'm unable to do yardwork. I'm active in my church and able to participate in some Boy Scouting, just not camping or anything too physical. One big detriment to this illness is that I look fine. Everyone asks me why I am on disability at such a young age. Putting on a "happy face" is not always that easy. I just do not go out as much as I would like, limiting my public contact for health reasons. My family misses the camping, skiing and other activities as do I, but life goes on to our best abilities! 🍀

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

The Painted Turtle Retreat Weekend

for Families With PIDD



Every once in a while we all need a break, and you might find yours at

The Painted Turtle, in Lake Hughes, Calif. The Painted Turtle is offering a retreat weekend for children with primary immune deficiency diseases (PIDD) and their family members, November 10 through 12, 2006.

This may be just the thing your family members need to unwind and enjoy each other in a setting that is perfectly accommodating of children with PIDD. The camp is open to 6- to 17-year-old patients with a diagnosed immunodeficiency and their family members. Thanks to the generous private donors who support The Painted Turtle, the weekend is offered at no cost to families. The camp can accommodate 25 to 30 families from California, Nevada and Arizona.

The Painted Turtle is the sixth addition to actor and entrepreneur Paul Newman's nonprofit association of Hole in the Wall Gang Camps for seriously ill children. It is the only multi-disease camp and family-care center of its kind on the West Coast. Through educational, therapeutic, safe and just plain fun summer-camp and year-round programs, The Painted Turtle provides a life-changing experience to children whose daily struggles often diminish both their desire to be well and their ability to lead a rich, productive life.

At first glance, a Hole in the Wall Gang Camp looks like any other traditional summer camp that offers swimming, boating, fishing, horseback riding, arts and crafts, ropes courses, a state-of-the-art gymnasium, and nature activities. Yet, look more closely and you will find that at The Painted Turtle, every child, no matter his or her illness or capacity, can participate fully in every single activity because of the subtle, yet liberating, access components built right into the camp facilities themselves.

Paul Newman started the first Hole in the Wall Gang Camp

in Ashford, Conn.

Over the past several years, he has expanded that vision by helping to establish camps in New York, Florida, North Carolina, Ireland, France, Africa, Israel and in California at The Painted Turtle. To date, these camps have served more than 70,000 children from 34 states and 27 countries.

The Painted Turtle was founded in 1999 by Paul Newman and Page Adler, who had volunteered at an East Coast camp and wanted to become more involved. Of the more than 1 million children in California with chronic illnesses, a needs assessment revealed that there are more than 17,500 youngsters who are unable to attend summer camp due to their medical needs. The Painted Turtle provides these children and their families with an empowering, renewing experience completely free of charge.

The medical needs of the campers are the top priority. The Well Shell, a 6,000-square-foot clinic, houses four colorful treatment rooms, a hemodialysis lounge overlooking the lake, two cozy home rooms, and a fully stocked pharmacy. The Painted Turtle has intentionally removed any hint of a hospital atmosphere. When campers visit the Well Shell they will not find white coats or white walls, but instead colorful wall murals and doctors and nurses dressed and acting like everyone else—informal, friendly and caring.

If your family is interested in attending this wonderful weekend retreat, please visit The Painted Turtle website at www.thepaintedturtle.org or call the camp at 661-724-1768 to be added to the mailing list for applications, which will go out in August.

Medical personnel interested in volunteering to staff the camp for the weekend should also call or visit the website. Infusion nurses who are familiar with immune globulin and immunologists are especially encouraged to volunteer. ■

Everything You Ever Wanted to Know About...

...Guillain-Barré Syndrome (GBS)

Websites and Chat Rooms

1. The GBS Foundation International, 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/.

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.
2. The Mayo Clinic has an overview of Guillain-Barré syndrome at www.mayoclinic.com/health/guillain-barre-syndrome/DS00413.

...Myositis

Websites

1.



THE MYOSITIS ASSOCIATION

The mission of The Myositis Association, www.myositis.org, is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. 202-887-0088
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, 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/.

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, for listings of support groups across the nation.

...Primary Immune Deficiency Disease (PID)

Websites and Chat Rooms

1.



IMMUNE DEFICIENCY FOUNDATION

The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is dedicated to improving the diagnosis and treatment of PID through research and education. 800-296-4433
2.



The Jeffrey Modell Foundation, www.info4pi.org, is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency. 212-819-0200
3. The National Institute of Child Health and Human Development (NICHD), www.nichd.nih.gov/, is part of the National Institutes of Health. Go to the "Health Information and Media" tab on the website and do a search under "primary immunodeficiency."
4. The American Academy of Allergy, Asthma & Immunology, 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, offers in-depth information on immunology, PID and treatment with intravenous immune globulin.
6. The Michigan Immunodeficiency Foundation, www.midf.org, seeks to improve the quality of life for Michigan residents affected by PID.
7. The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PID patients.
8. To connect to a PID message board, go to www.jmfworld.com.
9. To chat with peers on IDF's Forum, go to www.primaryimmune.org.
10. Chat with parents of children affected by primary immune deficiency at <http://health.groups.yahoo.com/group/PedPID/>.
11. Chat with peers with PID at <http://health.groups.yahoo.com/group/PIDsupport/>. ➤

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/ 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.
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.

...General Resources

Product Information

1. To learn more about Vivaglobin—the subcutaneous immune globulin (SCIG) recently granted FDA approval—go to: www.vivaglobin.com.
2. For more information about the new 10% IVIG solution Gammagard Liquid, go to www.gammagardliquid.com.
3. Learn about IVIG treatment with Gamunex at 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.
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.
3. The nonprofit Patient Advocate Foundation, 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, 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, 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.
7. The National Organization for Rare Diseases, at www.rarediseases.org, provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.
8. American Autoimmune Related Diseases Association (AARDA) www.aarda.org brings national focus to autoimmunity through research, education and patient services. 800-598-4668.

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.
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 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.
6. "The Confused Consumer's Guide to Choosing a Health Care Plan: Everything You Need to Know," by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.
7. "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.
8. "If You're Having a Crummy Day, Brush Off the Crumbs!," by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.
9. "Inclusion-Body Myositis and Myopathies," by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.
10. "Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration," by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.
11. "Managing Pain Before It Manages You," by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.
12. "Medifocus Guide to Peripheral Neuropathy" is a guide to current and relevant PN research, organized into categories for easy reading.
13. "Myositis—A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References," by ICON Health Publications, is a three-in-one reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.
14. "No Laughing Matter," by Joseph Heller (the best-selling author of "Catch-22"), who teamed up with Speed Vogel, his best friend, to describe Heller's battle with and triumph over GBS.
15. "Not Dead Yet: a Long Strange Trip From Doctor to Patient and Back Again," by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.

Everything You Ever Wanted to Know continued...

16. "Numb Toes and Aching Soles," by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
17. "Numb Toes and Other Woes," by John Senneff, is the second in a series of three books. It focuses on clinical findings and treatment strategies for PN.
18. "Nutrients for Neuropathy," by John Senneff, the third in the Numb Toes series, is focused exclusively on nutrient supplementation as a means for managing PN.
19. "The Official Patient's Sourcebook on Inclusion Body Myositis," by James N. Parker (Editor) and Philip M. Parker (Editor), is a reference manual for self-directed patient research.
20. "Pride and the Daily Marathon," by Jonathan Cole, describes how Ian Waterman was suddenly struck down at work by a rare neurological illness that deprived him of all sensation below the neck, and how he reclaimed a life of full mobility.
21. "Pronoia Is the Antidote for Paranoia," by Rob Breznsy, explores the best way to attract the blessings that the world is conspiring to give us.

IG Manufacturer Websites

Baxter: www.baxter.com
 Grifols: www.grifolsusa.com
 Octapharma: www.octapharma.com
 Talecris: www.talecris.com
 ZLB Behring: www.zlbbehring.com

Pump and Needle Websites

Intra Pump Infusion Systems: www.intrapump.com
 Repro Med Systems, Inc: www.repro-med.com
 Graseby Marcal Medical: www.marcalmedical.com
 Norfolk Medical: www.norfolkmedical.com

...Nutrition

For help contacting medical professionals who understand the links between nutrition and medicine, consult one of the following links.

American Board of Physician Nutrition Specialists
<http://www.ipnec.org>

American Dietetic Association
<http://www.eatright.org>

American Gastroenterological Association
<http://www.gastro.org>

**North American Society for Pediatric Gastroenterology
 Hepatology and Nutrition**
<http://www.naspagn.org/>

...Scholarships

Immune Deficiency Foundation Scholarship

This award is available to individuals diagnosed with a primary immune deficiency disease. <http://www.primaryimmune.org/services/scholarship.htm>
 800-296-4433

The ELA Scholarship

This scholarship provides financial assistance to women with physical disabilities who are enrolled in a graduate program in a college or university in the United States. <http://www.ela.org/scholarships/scholarships.html> 626-398-8840

Bank of America Abilities Scholarship Program

These scholarships are awarded to students with disabilities who have a career interest in finance, business or computer systems. http://www.scholarshipprograms.org/bada/bada_2005_ins.htm 864-268-3363

Foundation for Exceptional Children

The Stanley E. Jackson Award for Gifted/Talented Students is awarded to students with a disability. <http://yesican.cec.sped.org/scholarship/index.html>
 800-224-6830

Joyce Walsh Junior Scholarship for the Handicapped

This scholarship is awarded to disabled instrumentalists or vocalist members of National Federation of Music Clubs. <http://www.mfmc.net/scholarships.html>
 317-638-4003

Panasonic Young Soloists Award

This award is given to vocalists or instrumentalists under age 25 who are permanently disabled and interested in studying music. http://www.panasonic.com/corp_cont/celebrating.asp 202-628-2800

Horatio Alger Association Scholarship Program

The Horatio Alger Association provides financial assistance to students who have exhibited integrity and perseverance in overcoming personal adversity and who aspire to pursue higher education. <http://www.horatioalger.com>
 703-684-9444

Central Intelligence Agency: Undergraduate Program

The CIA Summer Internship Program is open to undergraduate students, particularly minorities and people with disabilities, who have completed one or two years of college-level academic study. <http://www.cia.gov/employment/student.html>
 800-368-3886

Through the Looking Glass

This nonprofit offers college scholarships for individuals with parents with disabilities. www.lookingglass.org 800-644-2666

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