

You Need Help; I Want to Help Why Doesn't It Feel Good?

 The Barriers to Effective Support



**'Tis the Season to
Eat Healthier**

**How Can We Secure
the U.S. Pharmaceutical
Supply Channel?**

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

A community service from FFF Enterprises and NuFACTOR Specialty Pharmacy

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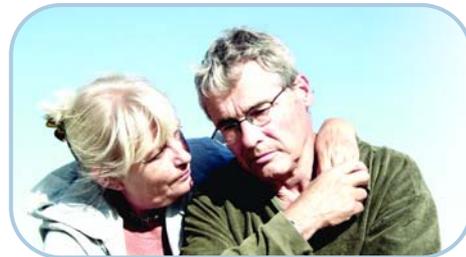
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About IG Living

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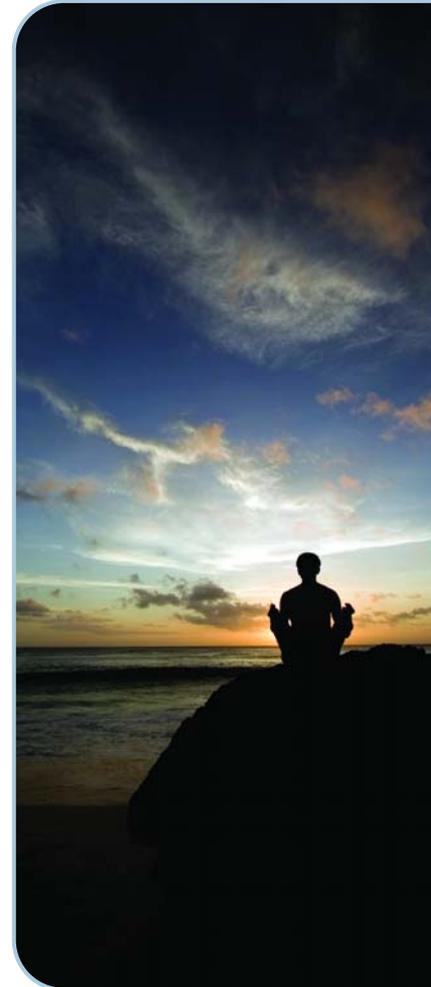
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Join an IGL Readers Group!

We hear from many, many patient and family member readers who would like to connect with others in their geographic areas—to share their experiences living with chronic diseases or maybe just to have a cup of coffee with folks who understand.

We can help you determine if there's a patient organization support group in your area or help you start an IG Living Readers Group.

To join a group or start one in your own area, visit www.igliving.com and click on IGL Readers Groups.

The Measure of a Country's Greatness

"You're not a patient, you don't understand, you don't care!"

It was a startling statement, given the work we do (and, as the acquiescent owner of a couple of chronic but manageable ailments, I can actually offer up the occasional commiserative diagnostic or hospital-visit horror story). But it was a heartfelt comment and, hence, warranted some consideration.

Is compassion dependent upon a commonality of experience? Can someone who suffers a little truly understand someone whose suffering seems greater? Must one have myasthenia gravis to possess a sympathetic perspective of an MG patient? Or bear the pain and weakness of CIDP to comprehend the burden? Or live with a primary immune deficiency to empathize with those with the same diagnosis?

What about physicians? Do you suppose they are insensitive healers until they experience the fear and anger and sorrow of a serious diagnosis of their own?

Well, we've met some very caring doctors through *IG Living*. They write thoughtful answers to our readers' questions late at night. They kindly review our articles in their limited free time. They continue to treat patients on immune globulin (IG) therapy at a loss. Are they the exception or the norm? Would—could—becoming chronically ill make them any more caring?

What about politicians, those upon whom we are relying to solve the IG reimbursement crisis? Although many of them are oblivious to the cause, the leaders of the effort surely care, but they are not all chronically ill. Is it possible that Nebraska Senator Abbie Cornett, a CVID patient and chair of the new Alliance for Plasma Therapies, cares more than Congressman Steve Israel who has spent the last two years advocating for fair IG reimbursement and a secure pharmaceutical supply channel?

I'm not convinced.

Countless experiences with exquisitely compassionate people—healthy and ill—seem to preclude any distinction in the depth of their caring. Rather, the character of the person is as likely to define the capacity for understanding others' suffering as is a person's diagnosis or lack thereof.

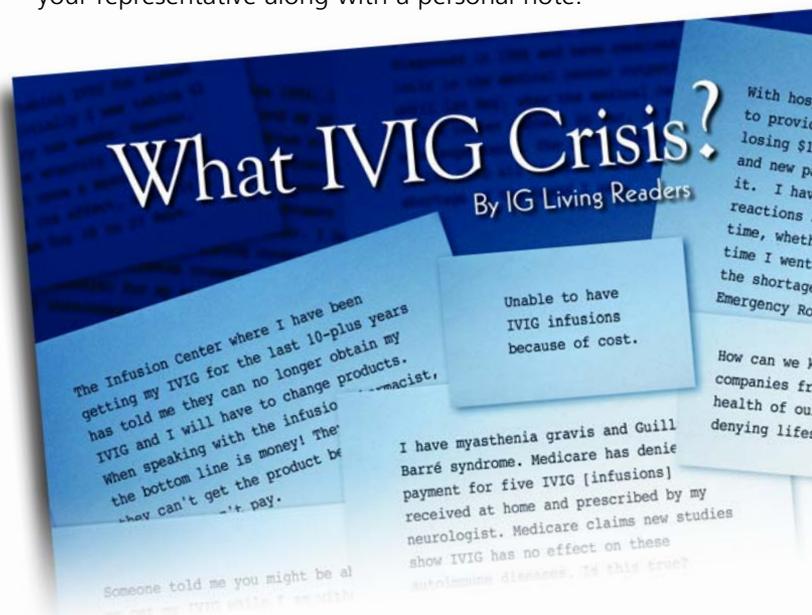
Nonetheless—and perhaps this is a mean thought—don't you suspect the IG reimbursement problem would have been resolved long ago, were there more politicians, more bureaucrats, more insurers, more family members of all three

living with diseases treated with immune globulin products? Then they'd surely understand.

But, yes, it is probably an unseemly thought—and an unnecessary solution.

Does anyone really understand anyone else? Probably not, not completely. But anecdotal evidence suggests that gaining a little understanding of someone else's suffering most often results in an increased level of caring—regardless of health status.

So take a few moments to help your member of Congress understand the importance of IG to people whose health depends on it. We'll make it easy for you! Just email us your postal address, and we'll send you a poster-size copy of our "What IVIG Crisis?" collage, so you can mail it to your representative along with a personal note.



U.S. Supreme Court Justice Thurgood Marshall wrote "the measure of a country's greatness is its ability to retain compassion in time of crisis." My bet is your representative will care.

Email your address to editor@igliving.com. ■

Kit-Bacon Gressitt, Editor

Please send your letters to the editor to editor@igliving.com.

Conference Connects and Inspires

By Dayna Fladhammer

The Immune Deficiency Foundation (IDF) held its fourth biennial conference in St. Louis, Mo., in June. The conference theme, “Catch the Spirit of IDF,” attracted people from 46 states, Mexico and New Zealand. For three days, participants were able to attend sessions focusing on distinct areas: scientific and life management. Presentations covered nearly every aspect of living with a primary immune deficiency disease (PIDD) as a patient and as a caregiver: Topics ranged from “Antibiotic and Antifungal Therapies” to “Caring for the Caregiver.” And the phenomenal keynote speaker, Alan Hobson, personified the theme of the meeting with his inspirational achievements, including his recovery from leukemia and his successful ascent to the summit of Mount Everest.

Despite all the great sessions, speakers and exhibitors, however, the best catch of the meeting was the connections made with other people—patients and caregivers.

For first-time attendees, discovering a community of peers—people struggling with the same healthcare and lifestyle issues—can be absolutely joyful and sometimes a bit overwhelming. It is not unusual that such connections bring people to tears. And, for people who’ve attended previous meetings, the experiences are often just as moving. The sense of community such meetings inspire is just as important as the information made available.

“I attended the IDF conference to support my niece, a 16-year-old diagnosed with autoimmune Evans syndrome,” said Deborah Bent of Wisconsin. “I met PIDD patients and their family members from a wide range of ages. All were eager to share their experiences. Of these, several stood out in particular. One was a family with three young children, all who have PIDD, one of which was receiving IVIG therapy. Another was a woman from Texas whose sister had traveled from Denver to support her. Perhaps the most poignant was a young man from

California who recently received a diagnosis of PIDD. He was still coming to grips with how the disorder and modality of treatment would affect the rest of his life.

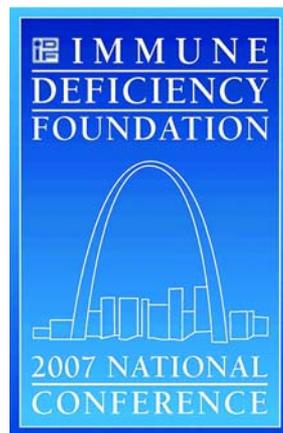
“I learned that people who are afflicted with PIDD will not allow the disease to define them; rather they will define the disease by arming themselves with knowledge. I came away with a real sense of community,” Bent said, “that we are all connected by the fabric of humanity.”

Marcia Boyle, the IDF’s executive director, hoped attendees would leave the conference inspired by new ideas and practical actions they can apply to their lives. “Empowering patients and families is a major part of our mission,” Boyle explained. “That comes from speaking with and learning from each other, as well as from our presenters. The conference is truly about our whole community, and all the good that happens when we get together!”

Boyle experiences the conference not only as an organizer but also as a parent of an adult son with PIDD. “For me, each conference is magical,” she said. “To see so many patients and families together is truly overwhelming. It is particularly exciting to see the hope and excitement expressed by patients and families who had previously never met another person who ‘speaks the same language’ or who had never before had access to a leading specialist.

“I come away energized from being with our community,” Boyle concluded, “with the drive to do much more. I believe that many others feel that way as well. For my son’s future, I want a strong IDF that can advocate for him and others like him, whether it is for health insurance, improved treatments or more research.”

Gail Bialke, a parent of a child with a PIDD, encapsulated the essence of what the IDF meetings offer. “Sitting and talking with other parents at lunch was so amazing,” she said. “For me, it was the best part of the whole conference.” ■





IG Reimbursement Cutting Healthcare Costs:

The Trend Toward Single Source Providers

Healthcare is expensive. In fact, the art of balancing the cost of healthcare with the quality of patient care is an inevitable evolution of the initial concept of health insurance, introduced in a 1694 publication by Hugh the elder Chamberlen. The fellow's entrepreneurial family developed the first obstetric forceps, which Chamberlen later marketed in Medieval Europe with mediocre success. The point being: although the benevolent natures of healing and caring are virtues, healthcare has been a business from day one.

Today, as office water-cooler conversations often drift to the seemingly perpetual increase in health insurance premiums in exchange for fewer services, no one seems untouched by the balancing act—cost and care, care and cost. But, for people with chronic diseases, including many of those treated with immune globulin, a reduction of services to balance increasing costs is a scary thought.

Hence, the current outcry against the health insurance industry trend toward what is known as “single source” or “sole source” providers for specialty pharmacy products and services:¹ Some U.S. insurance companies are transitioning the management of chronically ill patients' homecare and delivery of their specialty pharmaceutical products and services to a single, company-designated specialty pharmacy and/or homecare company.

For a patient receiving expensive home infusion services, such as intravenous immune globulin (IVIG) therapy, changing to a single source provider scenario means receiving product from a specialty pharmacy either owned or designated by the insurance company and receiving nursing services from the homecare company selected by the insurer, rather than by the patient.

Patients worry their quality of care is threatened by single source provider agreements. A recent public hearing about Blue Cross of California (BCCA), one of many insurers going the single provider route, attracted more than 200 patients and providers critical of the insurer, and BCCA's single source provider agreement took some direct hits. The Hemophilia Federation of America (HFA) wrote in a letter to the California Department of Managed Care, “Single source providers undermine many long established treatment protocols and the continuum of care relied upon by individuals affected by a bleeding disorder. HFA is adamantly opposed to this type of single source provider arrangement.”

Despite the opposition, insurers are following the single source provider trend for a sound financial principal, similar to buying in

bulk: Single source provision offers the potential for significant cost savings. A single provider represents to the insurer a reduction in the variety of transactions and processes required with multiple providers, and the ability to negotiate more favorable costs based on the volume of patients going to a single provider.

Although no insurers' estimates of potential cost savings were available for this article (one industry analyst did estimate 5 percent), a BCCA spokesperson was convinced the company would save money and benefit patients as a result of the insurer's decision to terminate its multiple homecare company agreements and enter an agreement with Anaheim, Calif.-based Crescent Healthcare to provide specialty infusion services.² “We truly believe that we're doing the right thing for the patients and for everyone involved,” said Zeinab Dabbah, MD, medical director of BCCA.

Dr. Dabbah explained that BCCA's costs for specialty pharmacy products and services had to be addressed. “A significant challenge for healthcare companies is to control the growing cost of specialty drugs. The healthcare industry is spending 20 percent more year-to-year on specialty pharmacy. It is truly unsustainable. ... For us to continue to provide the care, we must come up with ways to manage the cost.

“One of the things that came into play was acquiring our own specialty pharmacy, PrecisionRx,” Dr. Dabbah continued. “If you have a middle man, that middle man is always adding to the cost to make a profit. We looked into what is being provided on the specialty side that can be distributed directly from our own specialty pharmacy.”

Dr. Dabbah also addressed the special challenges to acquiring and treating with immune globulin products. “We recognize that IVIG is in a very unique position because there are several components: the product, manufacturer allocation, ancillary services and the nursing care. ... We recognize that this is a drug that requires sophisticated nursing and the tracking of a great deal of patient clinical information. In many cases, these patients haven't seen their physicians in six months or more. Some of them are being admitted to the hospital for treatment. We needed to identify a way to track all of this patient information to insure that they are receiving the appropriate care for their specific needs. The commitment that we received from Crescent is that we would receive clinical information that is complete and electronic, [and] adequate nursing and pharmacy support that provides thorough follow-up and clinical management.”

¹ Specialty pharmacy products include immune globulin, antihemophilic factors and other biological products.

² BCCA terminated contracts with at least 14 providers, including NuFACTOR, a sponsor of *IG Living*.

for Better or for Worse?

By Kit-Bacon Gressitt

Choice of Providers

One of the most common arguments against single source providers is the loss of choice. Jan Bult, president of the Plasma Protein Therapeutics Association (PPTA), said at the World Federation of Hemophilia's September 2005 meeting, "The PPTA opposes restriction of choice, preferred-drug lists, sole-vendor contracts, and restriction based on price."

While many patient advocates express similar concerns, that single source provider agreements will eliminate choice of providers—and cost them more, Dr. Dabbah challenged that interpretation of BCCA's offering. "Our intention is for our patients to pay less by using our providers. ... We are trying to insure that our patients have choices and options." Dr. Dabbah indicated the BCCA options include:

1. Hospital outpatient and inpatient treatment
2. Acquiring product through BCCA's specialty pharmacy, PrecisionRx, and using a home health agency nurse
3. Receiving product and infusion services through Crescent
4. Treatment in a physician's office.

"Another option for our PPO business," Dr. Dabbah said, "is to go out of network with another provider. However, the patient would then be responsible for the non-preferred provider costs."

One *IG Living* reader questioned that scenario. "PPOs are supposed to be about choice. Being forced to use one specialty pharmacy for home health is no different from having HMO-style care—while paying for PPO care." Other site-of-care options have become less viable because of reduced IVIG reimbursement: Hospital infusion clinics and physician offices are often not available to IVIG patients due to inadequate reimbursement.

However, for patients who prefer to remain with their current home-care provider, a PPO plan is one solution, if they can afford the plan and the out-of-network cost. But actual out-of-network costs can be difficult to determine. When asked for BCCA patients' costs, Dr. Dabbah could not be specific. "We have a nurse that's calling patients and telling them what the benefits are. The problem is there's not standard pricing."

Additionally, some insurers might indicate during open enrollment that certain specialty pharmaceuticals can only be acquired in-network, so going out of network might not be an option.

Specialty Pharmaceutical Utilization Review

Along with its transition to a single source provider agreement, BCCA has implemented a retrospective utilization review of specialty pharmaceuticals, including immune globulin products. According to BCCA's website, "pre-service medical review" is intended to "speed payment to providers and to help monitor the appropriateness of the

dose and frequency of specialty drugs."

Dr. Dabbah advised that patients become familiar with the utilization review concept. "It's important to understand utilization management review. For a layperson, we understand it can be very complex. However, anyone can look at our website and see what we have. The forms are quite easy to fill out and understand."

Like many insurers, BCCA's utilization review information can be accessed on the company's website:

1. Go to the BCCA homepage: www.bluecrossca.com.
2. Click on Providers.
3. Click on Pre-Service Medical Review for Specialty Drugs.
4. Scroll down for more information and required forms.
5. Utilization management guidelines can also be accessed from this page.

At BCCA, it is not a requirement that reviewing physicians' specialties are matched to the patient's disease. For instance, a primary immune deficient patient's review may not be conducted by an immunologist. Dr. Dabbah explained: "While we try our best to have a specialty match review, it is not something that we are mandated to provide. To insist on specialty match reviews up front in some situations could prove to be quite costly and unrealistic."

If a review results in a denial, the patient can appeal it. "The member has the right to request an independent medical review through the Department of Managed Health Care," Dr. Dabbah said. "If they uphold the denial, the member has a right to an administrative judge hearing."

The department can be reached by phone, 888-466-2219, and via their website. Go to www.dmhc.ca.gov and click on "Visit the HMO Help Center."

To avoid having to appeal a utilization review decision, Dr. Dabbah encouraged patients to work with their doctors. "Ask your physician to provide the requested information that we have described on our website. It is so simple. I cannot tell you how many hours we spent on this to make it this simple for our providers and members."

Conclusion

The effects of single provider agreements on access and cost of immune globulin therapy—and on the marketplace—are not yet known, although one industry analyst predicted that patients may have increased cost barriers to out-of-network providers. Given the number of unknowns, concerns are plentiful. We encourage affected patients and physicians to become familiar with such agreements and determine what options remain available to assure the highest quality of care in the most appropriate site for each patient. If you have a question, please contact *IG Living* at editor@igliving.com. ■

Readers Write



Your feedback, opinions, suggestions and anything else you'd like to share are important! Email us at editor@igliving.com or visit www.igliving.com and go to the Contact Us page to send your comments.

Dear Editor,

I have some good news. My daughter in California had knee surgery that didn't go well. She needed me, but I had not traveled for more than a week since starting SubQ a year ago. I was nervous about doing my SubQ away from home and flying with all the stuff on the airplane. Also, my husband had always helped me after our initial training so now I would be on my own. I had trouble getting the immune globulin from the bottle into the syringe, because I don't have a lot of hand strength, so that was always his job. But my daughter needed me, so I had to overcome my fear.

I got a letter from the doctor to carry the needles, meds, etc., on the plane. I used an insulated wine bag to carry the immune globulin and a plastic bag for the supplies. The pump has its own carrying case, which also held some bandages and alcohol swabs.

I was nervous at the security gate, but they never even asked me to open my bag and the letter was never needed. I had to change planes in Philadelphia, so I was traveling for about 12 hours. With the ice pack in the wine bag, the medicine was still cool when I got to California.

I stayed for an extended period and my homecare pharmacy had no problem sending me the immune globulin and more supplies as needed. I practiced one time at home doing it totally on my own before going to California, and felt good when I finished. A nurse gave me some tips on how to get the immune globulin out easier and it worked. This made me less nervous when doing it in California. My husband still likes to help me when he is home and I like his help, but I am grateful I am now totally independent.

Turns out my daughter needs me again, as she is facing more surgeries, but now I have no qualms about going!

—Sheila, Maryland

I really enjoy reading *IG Living* at my doctor's office. It has really opened my eyes.

— Virginia

When I was first diagnosed with polymyositis, my doctor told me I would be better in six months. It is now going on nine years, and I am still on the road to recovery.

The most important thing that I've learned from this disease is patience, because when you are faced with an autoimmune disease such as polymyositis, or any other, you are going to have your bad days and your good days. It's like an emotional roller coaster ride. One day you are up and one day you are down.

And then there are the side effects to all the medications that you are on that require more patience. Every time you start on a new drug, there is hope. Without hope, there is no power. So what I have learned is that you have to live one day at a time and just enjoy life, but with me, I take it one hour at a time.

—Michelle, Florida

I would like to see an article on multifocal motor neuropathy. I have been getting IVIG for this since December of 2002. I have been receiving your magazine for a few months now and find it interesting. Thank you.

Editor's note: Thank you for the suggestion. This article will be published in our December-January issue!

Our son is two and a half years old and began IVIG five months ago. He is a post-liver transplant patient who is immunocompromised. He has never felt better than these five months. Thanks for keeping us informed.

— Indiana

One of my patients let me preview your magazine. Thanks for all that you are doing.

— Infusion nurse, North Carolina

I know it must be hard for those who are having an issue with receiving their lifesaving IVIG treatment. Although I am currently receiving my treatment on a regular basis (I have common variable immune deficiency), I understand what it is like to feel blown away by a chronic illness.

Here is a poem I wrote when I was not receiving my treatment on a regular basis. It explains how I felt and how many people are feeling now. Just know that there is hope and everything happens for a reason.

This poem is directed to Congress: It explains how people will come to understand the problem of uncertain access to treatment, once it hits close to home.

Feeling Lucky Today

Waiting for that phone call
That today will be the day
No one understands how I feel literally blown away
Trying to get out of bed, but only feeling malaise
I continue to tell myself
That this is only just a phase
I get up day after day and do what I have to do
I can't believe that someone else's ignorance
Can prevent me from feeling like I can move
I continue to keep my head up
Because that is what's best for me
But it's hard to accept that I have no choice
But to depend on others completely
But God forbid that someone you love will feel this
way, too
Who knows, maybe by that point you'll finally make
your move

— Lauren Hermann

Nothing in this world is going to hold me back. The health problems I have endured have only made me a stronger person and given me a greater appreciation of what life is really all about. My prayers are with you all, especially those who are suffering from chronic illnesses. And my deepest prayers go out to the family members. It is much easier to be in the 'sick' position than it is to be in the 'person who cares about the sick person' position. I know it sounds weird, but the people who care about me have a harder time with my illness than I do. Just remember, when we're down, who is going to be there to pick you up—family and friends! So please keep your head up. I would like to make a dedication to my mom, Maia Hermann. She is the most wonderful person in this world. I love you with all of my heart and truly appreciate your love, wisdom and compassion.

Editor's note: Lauren is 20 years old and approaching her fourth year of college. She works at a community center as a recreation leader, focusing mostly on planning special events, and has accomplished a lot, despite her chronic illness.

I have CIDP. I had taken IVIG infusions for 12 months, for which my insurance provider paid, with no objection. I used an outpatient facility. They charged \$22,000 per treatment. The insurance provider paid approximately \$12,000 per treatment, which the facility accepted as full payment.

At age 65, I moved to Medicare and purchased a supplement. In order to receive the IVIG infusion I have to stay overnight in the hospital. The hospital charges \$44,000 per treatment, and Medicare pays \$2,700, which the hospital accepts as full payment. The outpatient facility told me they could not have accepted that small amount as it wouldn't cover their initial cost. There appears to be quite a discrepancy in the amounts paid and the amounts charged for which there seems to be no explanation. However, I'm grateful that I still continue to receive the monthly treatments with no out-of-pocket expense.

— Texas

Hereditary Antithrombin Deficiency

By Zachary Pugh

In 1965, hematologist Olav Egeberg examined a Norwegian family, members of which had been severely symptomatic of excessive blood clotting within the veins, a condition known as *venous thrombosis*. The results of his examination would change the hematology landscape forever. Egeberg concluded that the antithrombin levels for all of the family members with venous thrombosis were approximately 50 percent less than non-affected family members. This was the first case that provided solid evidence of a hereditary link between blood coagulation and thrombotic disease. Thus, hereditary antithrombin deficiency (HD) was born into the hematology community.

Overview

Produced in the liver, antithrombin is a crucial serine protease inhibitor of coagulation. People with HD produce low levels of, or nonfunctioning, antithrombin.

Literature and case studies on HD indicate it is a fairly rare condition. Dr. W. Keith Hoots concurs. He is a professor of pediatrics and the division head of pediatric hematology at the University of Texas Medical School at Houston and the section head of pediatric hematology at the University of Texas M.D. Anderson Cancer Center. Dr. Hoots says that about one in 3,000 people is diagnosed with HD and “most of those one in 3,000 are pretty mild.”

There are two major types of HD. Type I pertains to low levels of antithrombin (40 percent to 60 percent reduction), while type II HD patients produce defective antithrombin. The common thread between the two types is the risk of a thrombosis, which is a formation of a thrombus, or blood clot, within a blood vessel. “Most of the time the presenting symptom is venous thrombosis,” Dr. Hoots says, adding that this typically involves painful swelling in part of the leg.

Management

The main concern when managing HD is to decrease the risk of a thrombotic event. More than 85 percent of patients with HD will have at least one thrombotic episode by age 50. The incidence of thrombosis for women with HD has been reported to be 70 percent during pregnancy. Patients with hereditary antithrombin deficiency

are also at increased risk of thrombosis during surgery.

The literature on HD has split patient management into two broad categories: short-term treatment for patients in a high-risk situation and long-term treatment for those patients who have experienced thrombosis in the past.

The American Society of Hematology reports that “[w]hen considering the use of long-term prophylactic anticoagulation, in particular vitamin K antagonists, the benefits of the use of these agents must be carefully weighed against the risk of bleeding complications associated with their use.”¹

Situations that present a high risk of thrombosis require treatment with a therapy such as Thrombate III, manufactured by Talecris. Thrombate III is a concentrated human antithrombin, fractionated from human plasma. According to Dr. Hoots, high-risk situations include “when [patients] undergo surgery or when a woman delivers a baby.”

Treatment

As the only FDA-approved product for treating HD, Thrombate III provides crucial therapy to prevent thrombosis when patients with HD undergo obstetrical or surgical procedures. Thrombate III does not increase the risk of bleeding, possesses no known contraindications, has never been linked to the transmission of a virus and has been on the market for more than 15 years.² It is the only treatment indicated to restore hemostasis in these patients. Dr. Hoots affirms that if a patient has very low levels of antithrombin, the most effective way to increase the levels is with Thrombate III.

“FFP [fresh frozen plasma] is the only other alternative source,” Dr. Hoots says. However, there are dangers involved when using FFP. “There is a risk of pulmonary edema when there are volume constraints with the patient, and when it’s used in pregnancy,” he says, adding that “in older patients, there is a problem with using FFP.”

As always, the patient’s personal physician is the best source of guidance for what treatments are most appropriate.

For more general information, visit the National Alliance for Thrombosis and Thrombophilia at www.nattinfo.org and www.thrombate.com. ■

¹ Sanson B-J, Simioni P, Tormene D, et al. The incidence of venous thromboembolism in asymptomatic carriers of a deficiency of antithrombin, protein C, or protein S: a prospective cohort study. *Blood*. 1999;94:3702-3706.

² THROMBATE III [prescribing information]. Research Triangle Park, NC: Talecris Biotherapeutics Inc.; 2005.



Fingernails scraping the chalkboard make my skin crawl. Squashing a June bug underfoot is nauseating. And accidentally wiping a fresh paper cut with an alcohol swab is excruciating. But nothing pierces my senses like hearing, "The kids look great!" when my immune deficient children have been up half the night discussing what cool things they could do with their sinus drainage. (I'm thinking we might be able to pay for Caleb and Molly's college educations by marketing their green goop as holiday light adhesive—I am convinced it has the staying power of duct tape.)

I take offense when someone says the kids look healthy. I know it's sick to think a comment about Molly's "rosy cheeks" or Caleb's "robust appetite" could have such an effect on me, but I also know her rosy cheeks are from a battle with bronchitis and his robust appetite is a side effect of prednisone. I try to be gracious when speaking with others about the kids, but sometimes Momma Bear wants to put angry honeybees in the well-intended's underwear.

My husband, Mark, and I were recently asked to speak at a weeklong disabilities family camp. We were, thankfully, trained on how to interact in an appropriate manner with the people we'd meet there. For example, we were instructed to say someone "uses" a wheelchair, as opposed to saying he or she is "wheelchair bound." And the appropriate term is "person with a disability," not a "disabled person." Yes, my sensitivity radar was up and charged. A feeling of pride

Do You Hear What I Hear?

By Cheryl Haggard

swelled as I noted: *I'm not going to offend, as others offend me!*

I sailed though the week, savoring lighthearted conversations with folks who charmed and inspired me. Confident words of encouragement flowed easily between my new friends and me, and common ground was always found in a smile.

Until Friday afternoon.

I had just completed my tasty barbecue luncheon, when I spotted a young man standing awkwardly in a doorway. His stately features and stoic stare were picked up by my finely tuned sensitivity radar: This fine young man was, indeed, blind. Wanting desperately to demonstrate my well-seasoned ability to communicate with a "person with a disability," I

carefully approached the gentleman and introduced myself.

"Hello," I announced softly. So far so good.

"Oh, hello," he returned with a friendly grin.

Oh, I am a charmer, aren't I? I reflected. Then, without missing a beat, I asked, "Are you looking for someone?" *Looking for someone?* In one fell swoop, I was knocked from my throne and defrocked of my righteous royalty.

When my sensitivity synapses snapped to attention, I realized I had asked a blind person if he were looking for someone. "Oh my goodness!" I shrieked. "Did I really just ask if you were *looking* for someone?"

The kind man's face slowly gave way to gracious giggles.

"Yeah, you did, and how does your foot taste?" he laughed, diffusing a potentially awkward moment.

I packed our exchange in my heart as I stuffed my last pair of dirty socks into my duffel bag. This experience taught me that when it comes to my immune deficient kids, people just want to be nice and helpful, not cruel or mean-spirited. I am determined to choose laughter over getting bent out of shape when someone comments about how good my kids look.

And it dawned on me, if the community at large knew just how sick my kids really are, I might miss my opportunity to market "Caleb and Molly's Holiday Lights Adhesive" at the next holiday bazaar.

The potential loss of all that college money? Now that would be offensive. ■

The Dynamic Duo: Mothers and Daughters

By Ever Fecske

Is there an award for those mothers who don't spend their days volunteering for some large nonprofit or political party but, instead, give their all simply because they love? If there is, my mom, Fran, should win it.

By no means is my mother perfect, but she has an uncanny way of turning an unfortunate situation into something fun, interesting and, when it's all said and done, something not really so bad. Don't ask me how she does it, because I can only tell you that she does.

The last 23 years have been an adventure with my mother that I wouldn't trade for the world, regardless of its many low points. When we are together, we're like Lucy and Ethel. My mom is definitely Lucy, as she always seems to get us into places that spell trouble. There was the time she was caught snagging some latex rubber gloves—she'd never seen purple ones before!

Or maybe we're like Laverne and Shirley. I would be Shirley, always telling my mom, "No!"

Or better yet, we're like Carrie and Miranda. I'm Carrie because I love shoes, and my mother is Miranda. She can be painfully practical at times.

In every duo, these women have a special affinity for one another, and that's how I feel about my mother. We can go through anything together—and we have gone through a lot!

When I think about the amount of time and energy my mom spends on me, I feel so lucky. It's ironic how my illness has given us so much quality time together. I would never have gotten through the last two years without her. She is my partner in fighting the crimes caused by my common variable immune deficiency (CVID). She is my caregiver. And, actually, I am hers, too. We care for each other.

There are times when I am feeling lower than low and sorry for myself. That's when my mom swoops right in to give me all the positives of the situation or to take my mind off the pain, or she just gives me the

sympathy that I need. Regardless of what I need, we usually end up laughing.

A couple of months ago, I had an infection in my chest. I woke up at midnight, struggling to breathe. My chest felt so heavy, I couldn't get a good breath of air in or out, and there were shooting pains throughout my chest. I called my mom, and she was at my side in less than one minute. She crawled into bed with me and rubbed mentholated vapor rub on my chest. She did all she could to comfort me. Finally, we ended up on the living room couch, watching "Sleepless in Seattle." It was a scary, rough night, but having my mom with me made everything better.

We have traveled together to Colorado, Washington and all over California in our quest to find answers to my medical questions. We've lived out of suitcases, gotten caught in hail, snow and rain—and in elevators.

We are self-proclaimed nacho, buffalo wing and calamari connoisseurs, and we have a common character flaw: We both tend to flirt with cute doctors. I guess you can say



that my mom and I are in business together, the business of life with a chronic disease.

I have gotten through some of the most awkward, uncomfortable situations still smiling because of my mom. She has been there with me at every turn, every surprise, every crisis and dilemma. She has taught me that there is an endless supply of heated blankets in hospitals, and all you have to do is ask. She recommends taking full advantage of the chocolate pudding after any procedure. When having a CT scan with contrast, it is not only OK, but she insists on chocolate syrup in the barium to make it taste better. She fully encourages me to go ahead and sing out loud and dance around in my hospital gown after taking Ativan. She makes it clear to me that the calories in macaroni and cheese don't count after a lung biopsy, bronchoscopy or colonoscopy. And, a funny little surprise is mandatory after every traumatic experience: My mom always knows how to bring a smile to my face.

When it comes to my health, we discuss everything very openly, honestly, without any denial. I think she gave me this ability to face difficult things as we do. It's just the way we cope, wanting to know everything—about each other, my illness and sometimes the neighbors. (One time we were in a hotel and I caught my mom using a glass to listen to the couple next door to us. I found myself listening, too. They were pretty entertaining!)

My mom taught me early on that the more we know, the more we can help ourselves and others. My illness—our illness—is not the elephant in the room no one is talking about. We talk about her a lot, sometimes behind her back.

We do have our share of disagreements like any other mother-daughter or girlfriend team, but when we disagree about something medically, there is always a discussion, never a fight. We both voice our opinions and concerns, and, in the end, I know that it comes right down to my personal choice. Mom has told me that she trusts my instincts. Besides, our situation has truly put us on the same wavelength. Because we spend so much time together,



we often don't even need to speak a word to be able to communicate. My mother can just look at me, and I know exactly what she is thinking, although she rarely passes up an opportunity to speak.

A couple of months ago, we were driving home from an appointment, and I could tell there was something bothering her: She was being abnormally quiet. So I asked what was wrong, and my mom started to cry. She apologized for everything I had to go through and she wished she could fix it all.

I knew she felt helpless. I often feel that way, too, but this time it was my turn to comfort my mom. I reassured her that I believe everything happens for a reason. I pointed out to her how my illness has bonded our family like nothing else could have; that because of this elephant we all have spent more time together and really appreciate each other. Had the elephant never shown up, I'd be away at school in Boston and wouldn't have spent anywhere near as much time with my mom.

It's strange how unfortunate events create unbreakable bonds. I have had the time to realize how much my mom and my family love me and care for me. We realize how very loyal we are to each other, and we would stick by each other regardless of the circumstances because we have already survived so much.

The bottom line is this: We love each other. I would do anything for my mom and I know she would do anything for me—because she already has. I couldn't imagine going through any of this without her. She is so willing to take some of the load when the load is too much for me to bear.

Thank you, Mom. 🍷

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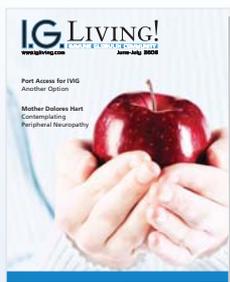
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Let's Talk!

By Shirley German Vulpe, EdD

If your life depends on immune globulin, this column is for you! It is an opportunity to network and share our experiences, because it behooves us to learn as much as possible about all of the ramifications of our illnesses. This column allows us to learn from one another. If you have a story you'd like to share, please email us at editor@igliving.com.

In this column of the "Let's Talk!" series, I interviewed 46-year-old Hunter, who is hoping that he will soon be able to receive the IVIG that can relieve the considerable pain with which he lives.

Shirley: Hunter, can you tell me a little bit about your illness?

Hunter: I have stiff person syndrome (SPS). It used to be called stiff man syndrome until recently. It actually occurs 60 percent of the time in women and is a very rare autoimmune disease. I believe I read diabetes occurs in 75 percent to 80 percent of SPS patients. Also, there has been a noted connection between SPS and some forms of cancer. I had cancer, metastatic carcinoma in the neck lymph nodes, in 2005. I was treated with radiation and chemotherapy, and have been cancer-free since then.

Shirley: Rare conditions are sometimes difficult to diagnose. Was yours?

Hunter: Indeed. I was initially misdiagnosed with spastic paraplegia. It started around 1998 with shaking in my right leg when I was cold. As time went on, the spasticity [stiffness] increased so much that I had to have an infusion pump in my abdomen that delivers a liquid medication, called baclofen, directly into my spinal fluid. It is a muscle relaxant and antispasticity agent. This method of delivery is much more effective. Without the pump I would not be able to move at all. As my disorder progresses, the pain has become horrible. I tried many oral

pain medications, patches, different types of injections, but nothing helped. I finally found a doctor that added pain medications to my pump along with my baclofen. We first tried morphine, but there were many side effects, so I switched to fentanyl, and it is more tolerable. In 2004, while trying to adjust my medications, a doctor noticed that I had rippling in the muscles of my arms and suspected stiff person syndrome. Previously I had been tested for all kinds of muscle diseases and nothing was confirmed. This time, however, the blood test for GAD antibodies confirmed that I had SPS.

Shirley: You sure have had a very difficult time of it!

Hunter: Yes, but worse was coming. Initially my ex-employer had very good medical insurance. Then he changed companies, and I got put on disability, which included Medicare. This change occurred when I was receiving IVIG treatment. I got it for two and a half months. IVIG has been found to decrease stiffness and pain, while improving function of people with SPS. There are two types of response to IVIG: rapid and slow. Unfortunately, I am in the slow class. Anyway, my IVIG was stopped, because Medicare and my co-insurance company would not pay for IVIG.

It is terrible, Medicare pays so little for IVIG that it costs providers money to give it to patients. It seems like the quality of life of persons with rare

conditions does not matter to our government. However, right now, I have a little bit of hope, as I am working with NuFACTOR, trying to get on IVIG.

Shirley: Have you found any other organizations or connections that offer support?

Hunter: One. Debra Kemery has a website support group. It was mentioned in the *IG Living* article in the April-May 2007 issue. Keeping track of discussions on her website helps me. ■

More Information

The National Institute of Neurological Disorders and Stroke (NINDS) has a concise information page about stiff person syndrome at www.ninds.nih.gov/disorders/stiffperson/stiffperson.htm. A NINDS-funded study "demonstrated the effectiveness of intravenous immunoglobulin (IVIG) treatment in reducing stiffness and lowering sensitivity to noise, touch and stress in people with SPS."

Although the NINDS site indicates there is no cure for SPS, it does report that IVIG treatment, anti-anxiety drugs, muscle relaxants, anti-convulsants and pain relievers improve SPS symptoms.

Debra Kemery's website is at www.stiffman.org.



'Tis the Season

Jessica Schulman, PhD, MPH, RD

"It's the most wonderful time of the year. With the kids jingle belling, and everyone telling you, 'Be of good cheer,' It's the most wonderful time of the year. There'll be parties for hosting, marshmallows for toasting..." (Eddie Pola, George Wyle, 1963)

The holidays are a great time to go on vacation, spend time with loved ones and enjoy the seasonal festivities. It's also a time when people travel, fall out of their routines and subsequently consume foods that are not aligned with their nutrition goals. This is particularly troublesome for those living with chronic health issues such as diabetes, food allergies, gastrointestinal conditions, kidney disease, metabolic problems and obesity.

With two-thirds of the U.S. adult population being overweight or obese,¹ most people will agonize over their waistline and about how to manage potentially stressful social interactions. Although scientists report that there is only a slight increase in body weight (approximately 1.1 pounds) after the Thanksgiving holiday,² there's often a significant increase in percent of body fat from before Thanksgiving to after New Year's Eve.³ The focus of this article is to review the new U.S. Department of Agriculture's MyPyramid, and describe healthy eating strategies that will assist readers in optimizing their intake during the most wonderful time of the year.

Tip #1: Develop a Plan of Action—There's Still Time!

To promote healthy holiday eating, the Centers for Disease Control and Prevention (CDC) suggests balancing the calories you consume with the calories you burn. It's easy, right? Simply make moderate food choices and be physically active (30 minutes or more per day). Easier said than done. A good starting point is to consider what things in life are controllable and what factors are uncontrollable. For example, if you are planning a vacation and have control over choosing the location, consider planning a retreat that

offers activities. That walking tour of the vineyards in Tuscany will do, but there are many other local and inexpensive options available. If the location is already determined by family commitments, you can still think about what you can do to make it a more active vacation. The CDC suggests bringing along your sneakers or snow shoes, taking a brisk walk or wheel around the neighborhood to see the holiday decorations (bundle up!), playing Frisbee with children and adults before the big dinner. Of course, some things will be out of your control, like sitting on the tarmac for hours as you become ravenous ... and those are the things you try not to worry about.

So, what can you control? Can you imagine yourself at the event? How might you react when you are standing before a table of turkey with gravy, sausage stuffing, sweet potatoes with caramelized marshmallow and pecan pie? It is essential to plan to be realistic about what you want to accomplish. Set reasonable and attainable goals during the holidays and set yourself up for success. For example, focus on weight maintenance and balanced eating rather than weight

Figure 1. Develop a plan of action, make healthy food choices and cultivate social support.



¹ CDC National Center for Health Statistics. Prevalence of overweight and obesity among adults: United States, 2003-2004. URL: www.cdc.gov/nchs/fastats/overwt.htm.

² Hull HR, Duncan R, Dinger M, Fields DA. The effect of the Thanksgiving Holiday on weight gain. *Nutrition Journal*. 2006; Nov 21;5:29.

³ Hull HR, Hester CN, Fields DA. The effect of the holiday season on body weight and composition in college students. *Nutr Metab*. 2006; Dec 28;3:44.

to Eat Healthier



loss and food restriction during the holidays. What follows are some additional behavioral strategies that might enable you to achieve your goals or help a loved one to optimize healthful eating during the holidays:

- Avoid starting a diet on Jan. 1. Such promises often excuse a binge in advance of a restrictive diet that is unlikely to last. Long-term weight management requires new habit formation and not a diet that has a specific start or end date. Consistency of food intake throughout the week and weekends predicts long-term weight loss maintenance.⁴ Seek support from a nutrition or behavioral counselor, or disease specific support group, for long-term habit formation.
- Try not to create “forbidden” foods unless it is medically necessary. This does not mean that all foods can be eaten with impunity. Rather, certain controlled amounts of favorite treats can be eaten as part of a balanced diet.
- Focus on an overall diet for the meal rather than on “good” or “bad” foods. In moderation, almost all foods can be incorporated into a healthful diet.

However, keep in mind that a long-term pattern of poor choices could cause dietary imbalances that contribute to obesity, diabetes, heart disease and so on.

- Don’t let “sometimes” foods, such as that bag of Halloween candy or leftover pie, become “everyday” foods. When you have leftovers, send these foods home with others or offer them as a gift of appreciation to your co-workers, nurses, household helpers and teachers. Some of our families may be ill or in the hospital during this time. Support caregivers with food. (Be sure to follow food safety guidelines.)
- If you allow your child(ren) to collect candy from the community, or you hand out candy and have leftovers, decide on an appropriate number of candies that may be consumed and donate or throw away the rest.
- Offer alternatives to candy on the holidays. One study showed that “children choose toys as often as candy when offered both on Halloween.”⁵ So don’t worry that children will be disappointed by toy treats on Halloween. It is possible to create holiday traditions that do not rely on unhealthful foods.

- Be mindful of the reasons and meaning behind celebrating the holidays together. Sharing food and feasting may be one tradition, but you can try to incorporate other things to make the season special. For example, bring photographs or stories to share, have an ornament exchange, decorate the Christmas tree, play a game of dreidel, bring out the instruments or check in with a loved one. Look for a quiet moment to ask how they are feeling.
- Offer to bring a dish to the event. This way, you will know that there is at least one dish that is safe for you or family members who might have special dietary needs.
- Give the host gifts that promote health. If children are present, bring items such as hover discs, jump rope, volleyball, roller skates, etc. Baskets of flowers, organic produce, dried fruits, teas and nuts are always thoughtful gifts.
- If you graze, try to munch on healthy foods such as fresh-cut vegetables and fruits rather than the holiday rum balls and cream cheese rugelach.
- If you are staying with family or friends, discuss your needs in advance. ➤

⁴ Gorin AA, Phelan S, Wing RR, Hill JO. Promoting long-term weight control: does dieting consistency matter? *Int J Obes Relat Metab Disord.* 2004 Feb;28(2):278-8.

⁵ Schwartz MB, Chen EY, Brownell KD. Trick, treat, or toy: children are just as likely to choose toys as candy on Halloween. *J Nutr Educ Behavior.* 2003;35:207-209.

How do you know if you're at a healthy weight?

Overweight and obesity are names used to indicate when an individual's weight is not considered healthy for his or her height. A body mass index (BMI) is used to identify ranges of weight that have been linked to health problems.

To determine whether you are under, over or at a healthy weight, go to the CDC's BMI Calculator at www.cdc.gov/nccdphp/dnpa/bmi/index.htm.

Tip #2: Make Healthy Food Choices and Celebrate the Event!

The U.S. Department of Agriculture has replaced the Food Guide Pyramid with MyPyramid as nutrition guidance for the general public.⁶ MyPyramid is not a therapeutic diet for any one health condition, rather it is a more individualized and up-to-date version of the Food Guide Pyramid. For example, greater amounts of fruits, vegetables and whole grains are recommended, and more specificity is provided regarding types of fat. Also, its guidelines are consistent with recommendations for managing obesity, diabetes, heart disease, stroke, high blood pressure, cancer and osteoporosis.

- Find the pyramid that is right for you by visiting www.mypyramid.gov. Create your own profile of foods based on your unique calorie needs. The MyPyramid recommendations provide sample diets that are nutritionally adequate. MyPyramid is designed for people 2 years old and older who are not on a therapeutic diet for

specific health states. Those with a chronic disease should consult with a healthcare provider to find a dietary plan that is right for them.

- Make half your grains whole.
- Vary your veggies.
- Focus on fruits, go easy on fruit juices.
- Get your calcium-rich foods, but go low fat or fat free.
- Know your fats, and consume most of your fats from fish, nuts and vegetable oils.
- Go lean on protein by choosing low-fat or lean cuts of poultry and meat.
- Integrate the turkey into other healthy dishes. Add some pieces to mixed greens, cucumbers, avocado, tomato or any other salad topping you like.
- Try eating or serving an alternative such as a grilled fish that is high in omega-3s (linked to reduction in inflammatory processes). There is no commandment that says you must have turkey and gravy or ham on the holidays.
- Focus on variety, moderation and balance of foods at events. Be aware of serving sizes.
- Be cognizant of recreational eating and, if you are noshing on empty calorie foods (i.e., high-fat or sugar foods that are low in nutrients), position yourself away from the buffet tables or food tray. Encountering high-risk eating situations, such as those during the holidays, may be better navigated if one is self-monitoring and aware of the surroundings.
- Drink plenty of fluids to avoid dehydration (or as directed by your physician). It is easy for your sensation of thirst to be dampened when you are traveling, socializing, distracted and out of your routine.
- Eat a healthy snack in advance of showing up at the event to curb your appetite.
- Enjoy the season! Slow down and pay attention to what you are eating and drinking.
- Choose beverages wisely. If you drink alcohol, do so in moderation (approximately two standard drinks for a man and one drink for a woman). Making good food choices is all about being cognizant of the foods that you are consuming. Alcohol diminishes good judgment and it is high in empty calories (the body metabolizes alcohol like a fat).
- It is advisable to abstain from alcohol when using prescription or over-the-counter medications.

Tip #3: Encourage Social Support — Help Promote Healthy Eating Behavior

Although there has been discussion in the media about the impact of genetics on weight, changes in the physical and social environment also lead to healthy eating or excess

⁶ Krebs-Smith S, Kris-Etherton P. How does MyPyramid compare to other population-based recommendations for controlling chronic disease? *J Am Diet Assoc.* 2007;107:830-7.

caloric intake and weight gain. Certain times of the year may discourage the development of optimal dietary patterns, and social support can help, or hinder, healthy eating behaviors.

- Keep holiday cooking safe. Follow the basic food safety steps as outlined in the article, "Food Safety: Home for the Holidays" in the December-January 2007 issue of *IG Living*.
- Wash your hands frequently for 20 seconds (about the length of time it takes to hum "We Wish You a Merry Christmas"). Frequent hand washing is one of the best ways to prevent the spread of germs. It's the combination of the soap and scrubbing action that helps dislodge and remove germs. When traveling, use soapless hand gels as directed.
- Be sensitive to guests who have special dietary needs. Acknowledging needs, rather than minimizing them, is a courteous and inexpensive gift that we can offer to caregivers. It is not easy to ask for help or support, so try to move toward accommodating the caregiver rather than pulling them toward someone else's agenda. For example, telling Gina that little Bobby is going to be "just fine" without taking steps to remove an allergic ingredient from her pecan pie is not in the holiday spirit. In another case, readers may be caring for patients with severe immune problems. A child may be regaining certain freedoms after a bone marrow transplant, so attending a holiday event requires extra caution on the part of the host and guests.

- Respect the privacy, and try to honor the wishes, of an individual who must follow a restrictive diet during the holidays.
- Be aware that genetics and the environment both play a role in whether or not an individual is satiated after eating a meal. Leptin (a hormone released by fat cells) suppresses food intake and can diminish the reward effect or pleasure that is associated with food. People have varying levels of this hormone. Consider offering healthy choices for the grazers and make it easy for guests to engage in activities unrelated to post-meal feeding.
- Don't let anyone drink and drive. According to the CDC, alcohol-related motor vehicle crashes kill someone every half hour.
- Ask how you can help and show responsibility toward one another. Be prepared to listen to a friend

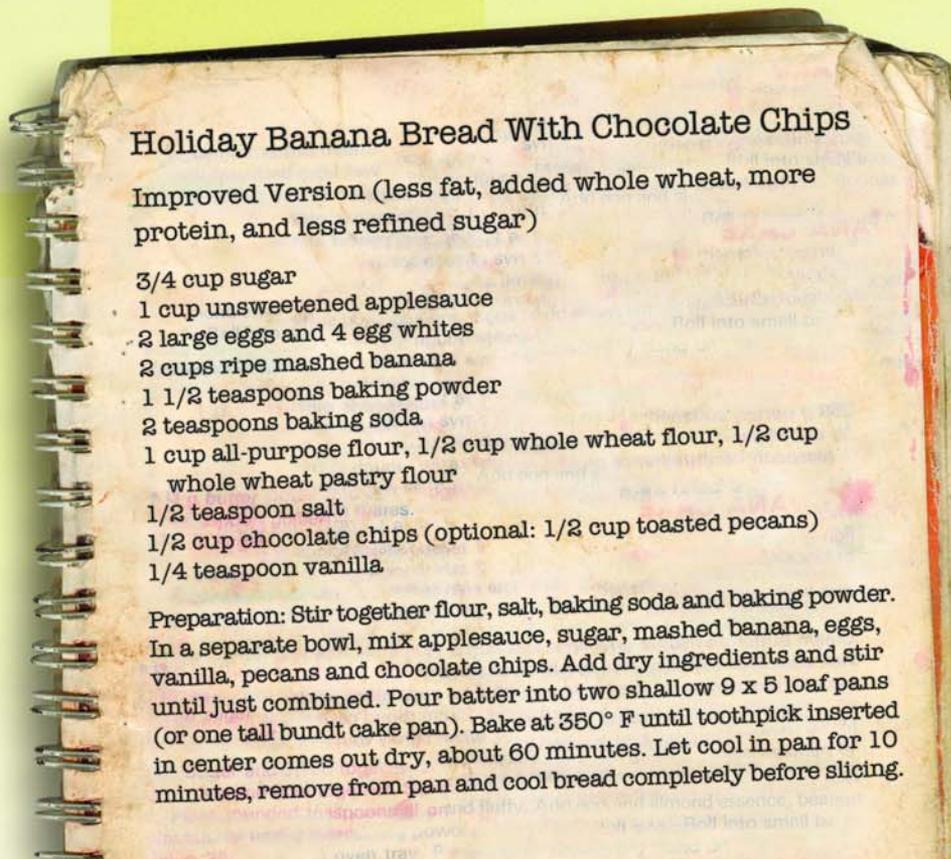
or loved one share anxiety or frustrations.

- Accentuate the positive. A disinterested or marginally involved partner or spouse will increase the likelihood that an individual will fail to adhere to a nutrition plan.
- Assist a working parent in making healthful foods for his or her family gatherings.

"There'll be much mistletoeing and hearts will be glowing, when loved ones are near. It's the most wonderful time of the year."
(Eddie Pola, George Wyle 1963)

Happy Holidays! ■

This article is intended for general informational purposes only. Individuals with a chronic condition should consult their physician to determine what eating pattern is appropriate for them. The author is a credentialed dietitian, holds a doctorate in health behavior, and is a visiting scholar in the Department of Psychology at the University of California, Los Angeles.



Motivating Cyrus

By Zachary Pugh

If you ask Cyrus Nallaseth about his accomplishments, he's likely to give a modest answer. But truth be told, his achievements, charities and reasons for giving back to the community are anything but modest—and he does it all while juggling a family, traveling the world and coping with chronic health conditions.

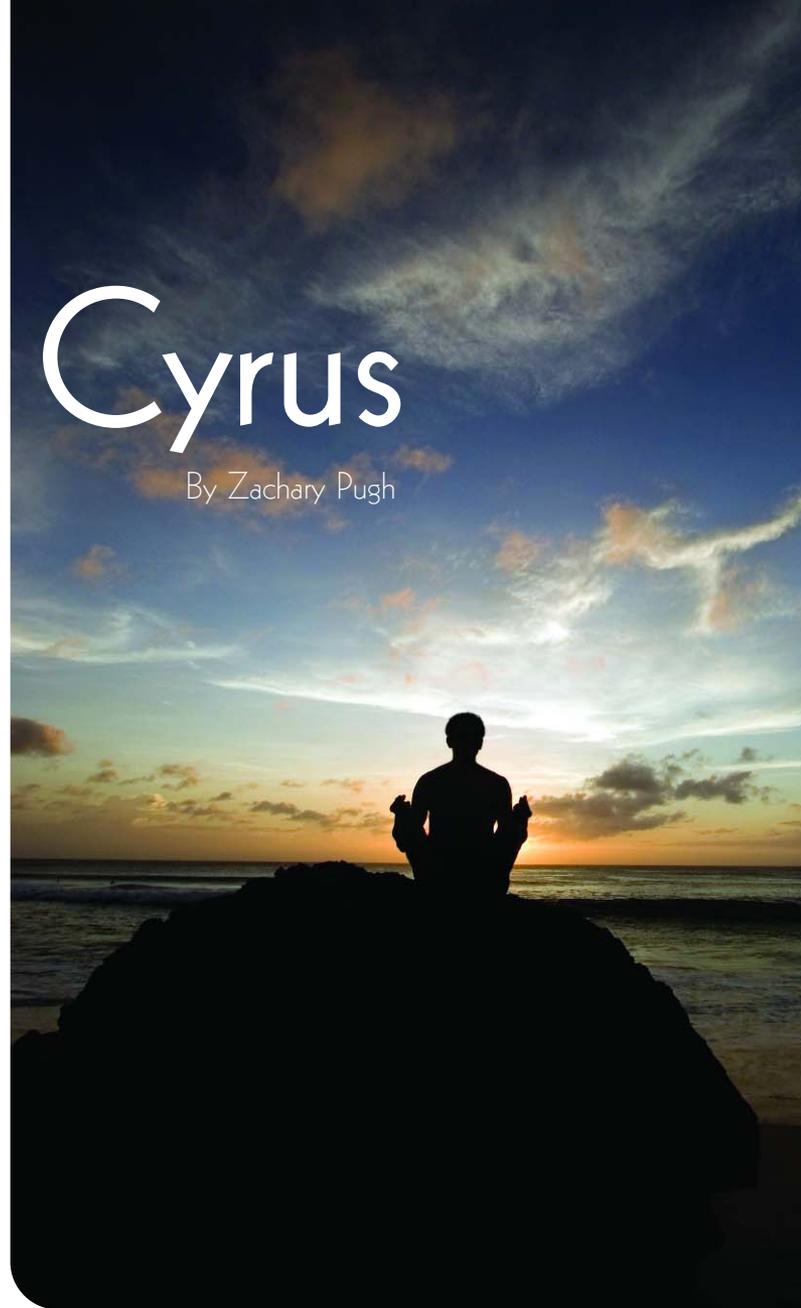
Cyrus Nallaseth was born into this world 50 years ago in Mumbai, India. After finishing his bachelor's degree in economics, he went on to study law at the University of Bombay, now known as the University of Mumbai. After completing his law degree, he moved to the United States and received his master's in business administration from the University of Missouri. While working as a senior executive for a U.S. bank, he completed the New York state bar examination and began to practice law.

Throughout his life, Cyrus has lived with a wide array of medical conditions. "I get pain in my nerves, muscles and joints. The pain migrates from place to place. The doctors have given me various diagnoses." Most recently, though, Cyrus has been diagnosed with neuropathy.

Despite his health, Cyrus contributes tremendously to those in India who are less fortunate than he.

"After 25 years in the United States, I returned to Mumbai and am opening an old-age home for the destitute and an orphanage," he says. "I have purchased a piece of land on the outskirts of the city, which is a little more than two acres in size," he says. On this lot, Cyrus is building a two-floor facility dedicated to those in need. "On the first floor I am going to house between 60 to 100 destitute elderly people. There will be no preference given to anyone from any religion, caste, creed or color," he says, adding that "the only qualification for admission will be that the person is destitute. We will pick up the elderly from the streets. I will provide food, clothing, medicines and everything they need to lead a satisfactory life."

Cyrus has used a clever entrepreneurial approach to fund his charity: "I have invested in a chain of pizza stores in India,



and all the profits from this business will go to the charity."

Although Cyrus says he has slowed down his lifestyle to improve his health, his philanthropic work keeps him quite busy. He also travels extensively between the United States and India on business, all the while managing his medical condition and saving time for his wife, a successful artist and film director, and two sons, 8 and 3 years old.

Cyrus is a true testament to human motivation, continuing to work, managing his disease and making a positive difference in the world—while trying to live a healthier lifestyle. In order to do this, Cyrus has had to make some important changes to his diet and his exercise routines. "I was a big 'foodie' and loved good food," he says. After



his neuropathy diagnosis, he became a vegetarian. "I used to detest fruits and veggies and only have meat, but now I am quite used to it," he says. "My eyes pop when I see a good steak, but I have strong willpower."

Along with a good healthy diet, Cyrus exercises his body and his mind regularly. "I swim at my country club, do yoga and walk on the treadmill. ... I meditate and do Pranayam, which is the single best thing for an autoimmune disease." Pranayam is a yogic breathing exercise that is believed to oxygenate the body and help heal the immune system.

As for coping with the pain that accompanies his neuropathy, Cyrus has installed a steam room in his home, and this helps alleviate his pain. "Besides my yoga teacher, I also get regular massages at home, which helps ease my pain," he says. "I meditate and sleep whenever I have pain." Cyrus is also on numerous medications.

Although Cyrus has explored immune globulin therapy—and homecare, which makes sense given his lifestyle—he is unsure if that's right for him. "I have decided to wait before I take IVIG. If my condition worsens, I will take the treatment, although I am not sure how much it will benefit me."

He does have some advice for those struggling to balance their lifestyle and their medical condition. He suggests not smoking and drinking alcohol; eating less sweets, meat and chicken; eating more fruits, veggies and uncontaminated fish; and taking vitamins regularly.

As for exercise and overall balance of life: "Exercise, even if you are in pain, but not if you have inflammation and are in a lot of pain. A little pain is OK as long as you do not stress your joints. Cycling, swimming and walking are good. Yoga and stretching are essential. Meditate, pray and keep stress levels down. Rest when you are in pain. Try to manage anger. Don't sweat the small stuff," he says, and adds, "Laugh a lot. Try to do something with a purpose in life." ■

Does IVIG Benefit CIDP Patients?

Recent studies have indicated that intravenous immune globulin (IVIG) therapy can be used to successfully treat CIDP. In the December 2001 study, "IVIG and CIDP" by Michael Rubin, reported in the magazine, *Neurology Alert*, 32 patients with CIDP "were randomized in a multi-center, double-blind crossover trial to receive either IVIG (2.0 g/kg over 1-2 days) or "oral prednisolone, tapering over 6 weeks from 60 mg/d to 10 mg/d."

Rubin reported that both prednisolone and the IVIG successfully treated the symptoms in the 24 participants who completed the trial. "Neither treatment demonstrated superiority over the other. Two weeks following randomization both produced significant improvement in the disability scale and in time to walk 10 meters."

Although both therapies treated the symptoms of CIDP, "psychosis occurred in one prednisolone-treated patient." Contrarily, "[n]o serious adverse events were seen in the IVIG group." Rubin concluded that "[p]rednisolone and IVIG are equally efficacious for the treatment of CIDP. "Although the former is inexpensive in the short term, long-term side effects of steroid treatment favor IVIG as the first-line therapy."

ASK KRIS



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

Melissa: I have polymyositis and am interested in information about using IVIG with rituximab.

Kris: We posed your question to Dr. Todd Levine of Phoenix Neurological Associates, and he provided the following answer:

The idea of using rituximab in polymyositis is a reasonable one. In fact, it is being studied in a randomized, placebo-controlled trial at the present time. However, there are no published reports of whether it would be effective. Rituximab depletes B cells, which may be important in the disease process in polymyositis. There is also no reason to believe that mixing IVIG and rituximab would have significant bad side effects. In fact, I have used this combination in other autoimmune diseases with some success. Therefore, while it is clearly off label, meaning it is not indicated by the FDA, it should be a safe combination therapy to try to see if it helps with your muscle disease.

There are many potential treatments and by far the most important issue is to work with your physicians to determine which combinations would be most helpful for you.

Shari: I have just begun IVIG therapy. How long does it take to see results? I was diagnosed with CVID and am low in immunoglobulins. Do people see results right away?

Kris: We asked a pharmacist working with primary immune deficient diseases to address your question. The following is his response:

Every patient responds differently to IVIG, and, in general, a six-month trial period is appropriate. Many patients notice an improvement after a couple of infusions.

It is important for all patients to keep a diary where they can track the number and severity of their infections. This is useful from a number of standpoints. First, since the improvement is generally gradual, it can demonstrate to the patient and the physician that the therapy is working. Second, it is helpful to have that information to provide to the insurance company when they are determining whether or not to continue to authorize the IVIG treatments. Finally, if the dose or frequency of IVIG infusions is changed, or if the brand of IVIG is changed, it is important to be able to show the effect this change has had, if any.

Shari, my kids have been on therapy for more than 16 years. IVIG has allowed them to have a very normal and active life. Our doctors always told us that, although IVIG will not keep my boys from getting infections altogether, we will see more good days, fewer infections and less severe infections. You should also be able to bounce back from infections easier. The important thing mentioned above is to keep a health diary. You will want to keep track of when an infection starts, when it ends and what medications you need to help with symptoms. In tracking the severity of an infection, it is important to use some kind of quantitative scale. For instance, try using a scale of 1 to 10, 10 being the worst. Physicians rely a great deal on what patients tell them. The more detailed the information you give the physician, the better decisions you and your physician can make. Remember, IVIG is not a cure, it is a treatment. The underlying immune medical condition requiring the treatment is still present. Therefore, common-sense precautions such as hand washing and avoiding unnecessary exposure to infection are always prudent.

Jerry: I have been prescribed penicillin for a tooth root canal. Is it OK to take it after my IVIG infusion?

Kris: We posed your question to Dr. Hans D. Ochs, professor of Pediatrics and Jeffrey Modell Chair of Pediatric Immunology Research at Seattle Children's Hospital, and his response follows:

I am not aware of any scientifically collected data about this, but this is my approach: Patients with anti-

body deficiency should try to schedule any invasive procedure right after an infusion of immune globulin. (If the patient is on SCIG, this special scheduling is not necessary, because they are infusing frequently enough that their trough levels don't have the peaks and valleys associated with less frequent infusions.)

If a normal patient would receive antibiotics for a procedure, a patient with PIDD facing that same procedure should have antibiotics also, but for a longer period of time.

Certain PIDD patients are at increased risk of sepsis or increased bacteremia (e.g., patients with chronic granulomatous disease, complement component deficiency, other innate immune defects such as IRAK4 deficiency, and patients who have had splenectomies). These high-risk patients should be covered with antibiotics if undergoing invasive procedures, including dental procedures or dental cleanings.

This is, of course, only one doctor's opinion, so be sure to always ask your own physician for guidance on the use of antibiotics.

Matt: Since there are so many insurance companies that are opposed to paying for IVIG, including Medicare, are there any manufacturers that are willing to help?

Kris: We posed your question to IVIG manufacturers and received the following responses.

Baxter, maker of Gammagard S/D and Gammagard Liquid, offers the GammAssist Program. The program provides a way for eligible users of Baxter's IVIG therapies to continue to receive their product without charge in the event of a lapse in private insurance. Any user of any of Baxter's IVIG therapies is eligible to participate in the program. For more information, visit www.immunedisease.com/US/patients/insurance/gammasist.html.

CSL Behring has several programs in place for patients:

The Reimbursement Resource Center is designed to provide helpful insights for understanding medical service costs and related insurance matters, including health insurance reimbursement for the CSL Behring product line. For more information call 800-676-4266.

The Patient Assistance Program provides medically necessary therapies to qualified patients who are uninsured or underinsured and for people who cannot afford their prescribed therapy. For enrollment forms or questions

about the program, please call 800-876-4266.

The Assurance Program is designed to assist patients on CSL Behring therapies who experience a lapse in third-party private health insurance. Call 866-415-2164. For additional information, visit www.cslbehring-us.com.

Octapharma USA's goal is to make sure that patients continue to receive the IVIG product they need in the setting best suited to their individual situations. In exceptional cases of hardship, Octapharma has provided short-term product assistance to patients who have otherwise been unable to access their lifesaving IVIG treatment. In addition, Octapharma provides a reimbursement information service to help steer patients through the complex funding pathways and a medical affairs service to provide clinical data to physicians to help them appeal in cases where either IVIG treatment or reimbursement has been denied. For more information, call Octapharma's toll-free number, 866-766-4860.

Talecris: For personalized assistance with coding, reimbursement and coverage questions, Talecris offers the Talecris Reimbursement HelpLine. The service is free, and reimbursement experts are available to assist Talecris customers from 8:30 a.m. to 5:30 p.m. (Eastern Time), Monday through Friday, at 877-827-3462. Additional reimbursement forms and resources are available at www.gamunex.com/Patient-Reimbursement.cfm.

Talecris also offers a Gamunex Emergency Supply Program for IVIG patients in critical situations related to their therapy, but unable to obtain treatment. Requests must be made by the prescribing physician, and there are pre-qualification guidelines. Emergency Gamunex is available on a first-come, first-served basis. To obtain a Gamunex Emergency Product request form, prescribing physicians should call Talecris Customer Service at 800-243-4153.

For patients who cannot afford or do not have insurance, Talecris supports Patient Services Inc. (see below).

Patient Services Inc. (PSI) is an independent non-profit organization that provides insurance premium and copay assistance. For more information about PSI, visit www.uneedpsi.org, call 800-366-7741 or email uneedpsi@uneedpsi.org.

Please note: Immune globulin manufacturers can assist only those patients who are using their products for on-label (FDA approved) purposes. ■

Have questions about living comfortably with your IG therapy?
Send them to editor@igliving.com or visit Ask Kris at www.igliving.com.



How Can We Secure

the U.S. Pharmaceutical Supply Channel?

By Kit-Bacon Gressitt

The often-postponed federal drug pedigree requirement, enacted in the Prescription Drug Marketing Act (PDMA),¹ was to have finally been implemented December 2006. It would require a pharmaceuticals distributor to document every entity that has had possession of a vial or bottle of medication the distributor handles. The common belief is that pedigrees will help secure the supply channel, preventing drug counterfeiting and diversion and the multiple transactions that often increase a drug's price and put it at risk of being mishandled.

Instead of being at long last implemented, the federal pedigree requirement has languished since December, awaiting resolution of a court challenge to its constitutionality. In the ongoing void of a nationwide requirement, individual states have tried to pass their own pedigree laws, resulting in mass confusion. Within the varying efforts to secure the U.S. pharmaceutical supply channel, "who's passed what and what's effective when" is more circular than the classic Abbott and Costello routine "Who's on First."

Worse, this has been the status quo for many moons. Despite the Food and Drug Administration's comprehensive 2004 report

"Combating Counterfeit Drugs" and its updates,² Despite the 2005 publication of the frightening exposé by Katherine Eban, "Dangerous Doses: A True Story of Cops, Counterfeiters and the Contamination of America's Drug Supply."³ Despite Florida's once passionate but ultimately tepid legislative effort to lead the nation in securing the pharmaceutical supply channel. Despite countless U.S. media reports of drug diversion, mishandling and counterfeiting. Despite the mournful and outraged pleas of families harmed by a channel lacking integrity. Despite all this, the U.S. pharmaceutical supply channel remains unsecured. This failure begs the question "How can we fix it?" and the answers vary, depending on who is asked.

FFF Enterprises, a specialty pharmaceuticals distributor and sponsor of *IG Living*, believes the solution is simple. "Don't do it—secondary distribution that is—just don't do it!" said Patrick M. Schmidt, FFF's president and CEO. Secondary distributors are those who buy pharmaceuticals from other distributors or from healthcare providers, rather than directly from manufacturers. "Ours is not a popular position," Schmidt said, "and some people in the industry think if you eliminate secondary distributors in an effort to secure the supply channel, there are U.S. sites of care we won't be able to reach. I don't believe that. Just ask FedEx or UPS or DHL."

¹ U.S. Prescription Drug Marketing Act of 1987: www.fda.gov/cder/regulatory/PDMA.

² "Combating Counterfeit Drugs" 2004, "FDA Counterfeit Drug Task Force Report" 2006, www.fda.gov/counterfeit.

³ "Dangerous Doses" by Katherine Eban, Pub. 2005; Reprint edition 2006, www.dangerousdoses.com.

FFF is a manufacturer-authorized distributor of record (ADR) for all U.S.-licensed plasma products, including intravenous immune globulin (IVIG or IGIV), a recognized target of diversion, unethical pricing and counterfeiting. Although ADRs are not required to provide pedigrees for medications purchased directly from manufacturers, FFF has been voluntarily providing electronic pedigrees for its customers since 2004. Yet Schmidt is not convinced pedigrees are the solution.

"I'm not sure the supply channel can ever be completely fixed, although there has been a lot of progress," Schmidt said. "But the pedigree requirement stops short as long as there are exemptions. ADRs and manufacturers should not be exempt. And now people know enough about pedigrees to be dangerous. Many providers know to ask for them but don't have the wherewithal to verify the pedigree information, and pedigrees can be counterfeited. We've seen pedigrees with transactions hand-written in."

In fact, FFF was recently provided copies of pedigrees obtained by the state of Georgia Drugs and Narcotics Agency in the course of an audit of a secondary distributor. The pedigrees, filled in by hand, documented several instances of IVIG transactions that began with FFF's purchase of the product from the manufacturer and sale to an infusion clinic. The infusion clinic sold the product to a physician who has a wholesale license. The physician didn't administer the IVIG to patients, but, instead, sold it under his wholesale license to a secondary distributor, which sold the product to another secondary distributor.

All told, the various secondary channel transactions reflected in the documents from Georgia resulted in price increases ranging from about 50 percent to 100 percent.

"We cut off the infusion clinic immediately, as did the manufacturer," explained Chris Ground, FFF's senior vice president of national accounts. "The clinic's sales of product obtained from FFF violated its agreement with FFF, its agreement with its group purchasing organization (GPO) and the GPO's agreement with the manufacturer. But the pedigree didn't stop the bad behavior; it just documented it. What the pedigree did *not* document was whether the IVIG was handled, stored and shipped properly; whether the temperature was maintained; whether the product's integrity was maintained. That IVIG was ultimately infused into critically ill patients, at an exorbitant price. Is that the IVIG you would want for yourself or for a loved one? To an informed reader, that pedigree tells a dangerous story; it doesn't do anything to instill confidence in the product."

If pedigrees aren't the fix, despite significant hope and dollars invested in them, the quest for channel integrity could become a windmill tilt. But Schmidt sees better defined business practices and a more astute buyer as the answer.

"Ultimately, the question is, do secondary distributors add value to the channel? We don't believe so," Schmidt said. "The secondary

channel exists to exist, to make money and to prey for shortages—and I mean that to be spelled p-r-e-y.

"FFF's distribution practices are a sharp contrast," Schmidt continued. "We purchase only from the manufacturer and ship only to the healthcare provider. That's the only true solution. That means no transactions between distributors, no manufacturer sales to unauthorized distributors, no secondary channel for healthcare providers to sell into. If all manufacturers, all ADRs and all healthcare providers accept this practice as the industry standard, the channel will be as secure as it possibly can be, and we won't need regulation. Short of that, it's the government's responsibility to protect its people."

Jayne E. Juvan, a healthcare law attorney with Benesch, Friedlander, Coplan & Aronoff, posts a health law blog⁴ where she has tracked the legal challenge to the federal pedigree requirement. The case was filed against the U.S. Department of Health and Human Services (HHS) by a group of secondary distributors (those who are not ADRs), led by RxUSA Wholesalers Inc. The plaintiffs are opposed to the federal pedigree requirement that exempts ADRs.

“Don't do it—secondary distribution that is—just don't do it!”

Patrick M. Schmidt, FFF Enterprises

"RxUSA has argued that the law is unconstitutional because it treats different classes of individuals differently without having a rational basis for doing that," Juvan said, but she went on to explain that "[t]he Constitution allows us to do that. ... If it doesn't involve race or a fundamental right such as voting, the courts generally follow Congress."

Juvan expressed no expectation that RxUSA will prevail, but indicated the case could take years, holding up the federal pedigree requirement. Yet she echoed FFF's doubt that pedigrees can actually secure the supply channel.

"Supposedly, the average consumer stands to benefit from a more tightly regulated supply chain," Juvan said. "Whether that's actually [the case] is another question. Do the regulations make it less likely for counterfeits to make their way into the supply chain? There are arguments both ways."

And the argument has shifted to the states, a trend Juvan suggests could actually hinder channel integrity. "The federal government should say that states cannot legislate [pedigree requirements]," Juvan said. "Multiple standards could actually increase the ➤

⁴ www.JuvansHealthLawUpdate.com

likelihood that counterfeits will be introduced and could impede distributors' ability to conduct business."

While pedigrees remain the talk of the town, some industry watchers assume the U.S. supply will always have a percentage of counterfeit drugs. "The key," Juvan said, "is to make sure our percentages don't rise."

In 2005, **Congressman Steve Israel**, N.Y. 2nd District, introduced HR 2345 (commonly known as Tim Fagan's Law⁵) after hearing about then-16-year-old Fagan, an organ transplant patient, being infused with counterfeit Epogen. The boy's medicine went through 11 transactions between the manufacturer and the Fagans' refrigerator, including a deal at a strip club in Florida. Among other channel safeguards, HR 2345 would require drug pedigrees—paper or electronic—of all distributors, mandate manufacturer reporting of counterfeiting within two days, give the FDA drug recall authority and increase criminal penalties for counterfeiting.

The bill didn't progress in the Republican-controlled Congress, but with the transition to a Democratic majority, Israel's office is now preparing to reintroduce the bill in a form "very similar" to its original.

"If every member of Congress had a Tim Fagan in every district, this bill would have passed two years ago," Israel explained. "I would argue that every member *does* have a Tim Fagan, but the nature of counterfeit medicine makes it almost impossible to recognize that.

“Counterfeit medicine is now one of the fastest growing criminal enterprises in the U.S. It's easy to do, it's hard to get caught and it's highly profitable.”

Congressman Steve Israel, N.Y. 2nd District

There's no question that the economics of this issue have helped stall any progress on this bill, but even the industry has come to a fairly recent recognition that the threat of counterfeit medicines and a growing gray market are far greater challenges to their profits than paper pedigrees and increased FDA enforcement. Counterfeit medicine is now one of the fastest growing criminal enterprises in the U.S. It's easy to do, it's hard to get caught and it's highly profitable."

Although Israel's bill would eliminate the ADR pedigree exemption, essentially resolving the RxUSA case, it would not put an end to the types of transactions that inspired the bill. "I don't want to wipe out the secondary market," Israel concluded. "I just want the secondary market to thrive with a distribution system that has integrity. Sending Tim Fagan's Epogen to the strip club tells me there's a lack of integrity in secondary channels."

The **HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE)** recently released a report on intravenous immune globulin.⁶ The report highlights some key characteristics of the secondary distribution channel:

"The IGIV marketplace has struggled with channel integrity and includes a significant secondary market outside of the authorized distribution channels. The secondary market is characterized by fluctuating prices and product availability.

"Prevailing IGIV prices in the secondary market are substantially higher than those in the authorized channel.

"In the last few years, in order to increase the integrity of the supply chain, each IGIV manufacturer has significantly reduced the number of its authorized distributors in the United States. Previously, manufacturers used large numbers of distributors, some of which were involved in reselling IGIV at a profit to other distributors (also known as the secondary market).

"Most manufacturers interviewed reported having a policy to eliminate any business relationships with an entity that supplies the secondary market. ... While IGIV manufacturers contend that they only sell to authorized distributors and providers, input from other sources contradicts this assertion. One GPO interviewed for the study reported that some manufacturers do indeed sell to secondary distributors at prices higher than that for allocated IGIV. Further, a secondary distributor interviewed for the study also indicated buying IGIV they sell directly from an IGIV manufacturer."

Flemming Nielsen, general manager of Octapharma USA, a global manufacturer of IVIG, confirmed some of the report's findings. Octapharma has reduced the number of its ADRs to five since entering the U.S. market in 2004, in an effort to secure its piece of the channel.

"Our direct distribution agreements indicate that our products are not for resale," Nielsen explained. "What usually happens is someone has acquired Octagam, and they call and want verification of the pedigree. Then we look into it and we get documentation that the product had been resold two, three, four times. We see that we sold it to the distributor, the distributor has sold it to the provider and then it has been sold out the back door. We will then tell the distributor not to sell to that provider anymore. ... We want to see that [it goes]

⁵ What does Tim Fagan's Law do? www.house.gov/israel/issues/counterfeitdrugs.htm.

⁶ U.S. Department of Health and Human Services, Office of the Assistant Secretary of Planning and Evaluation (ASPE), Analysis of Supply, Distribution, Demand and Access Issues Associated With Immune Globulin Intravenous (IGIV), February 2007: <http://aspe.hhs.gov/sp/reports/2007/IGIV/index.htm>.

from Octapharma to the distributor to the healthcare provider to the patient.”

Octapharma’s approach is labor intensive, which may not be feasible for big pharmaceutical companies. Nonetheless, Nielsen does see a channel integrity solution, one that isn’t regulated. “We sincerely believe that if you want to secure the channel there has to be a cooperative approach. ... As soon as [product] enters the channel, there has to be cooperation between the manufacturer, the distributor and the provider. We should be the ones to work this out together because we all want safe product and a secure channel for the patient.”

Martha Harbin was an organizer with Safe Drugs Now, a now-defunct consumer group formed to maintain the original requirements in Florida’s pedigree law. She believes she saw the government bow to the influences of business when the big three pharmaceutical wholesalers successfully lobbied the Florida Legislature to insert an exemption from pedigree requirements for ADRs in Florida’s law.

“We found some solace from watching the manufacturers’ press releases. They started announcing that they were voluntarily implementing some of the things that would have been required [by Florida’s law]. Like Pfizer announcing they wouldn’t sell to secondary distributors anymore.”

Harbin has come to believe the solution cannot be found at the state level. “If we continue to rely on the states to be the gatekeepers, there will be bad things happening. It’s going to take more for the public to become more involved and demand political change. It will take more media. The occasional instance of counterfeit drugs is not enough. I hope it’s not going to take something like the Tylenol situation in the ‘80s, but that was dramatic enough that it really caused a widespread awareness of the problem.”

Realistically, the public is slow to rally around a cause so difficult to understand. Today’s pharmaceutical supply channel is a tangled web, regardless of deceptive or honest practice: It is complex!

But, in a report to **U.S. District Court Judge Joanna Seybert**, presiding over the RxUSA v. HHS case, there is a seemingly quiet little statement that is actually screamingly simple: “[The Plaintiffs] purchase pharmaceutical products for resale almost exclusively from authorized distributors and not directly from manufacturers—primarily because manufacturers typically refuse to sell product directly to the Plaintiffs.”

That, coupled with the PDMA companion report by the Committee on Energy and Commerce that found “most of the drugs that were counterfeits, stolen, expired, or obtained through fraud were handled by secondary wholesalers” begs another question: If many manufacturers will not sell to secondary distributors and if secondary distribution is the primary entry point to the channel for dangerous drugs, can the

industry—can healthcare consumers—continue to tolerate the risks inherent in the secondary channel?

Harbin advocates for safety first: “[The manufacturers and distributors] need to put the safety of the consumer above everything else. They are in a unique position of public trust and that should motivate everything they do. In the end, that’s good business.”

“It’s going to take more for the public to become more involved and demand political change.”

Martha Harbin, Safe Drugs Now

Good or bad, how the business of distributing pharmaceuticals will be regulated is unclear. National pedigree requirements remain stalled in the miasma of a court challenge. Pending state pedigree requirements have not resulted in an enthusiastic rush to comply with their intent—in fact, some industry meetings addressing state laws have been, at times, focused on forestalling the requirements if not outright avoiding them. Other states continue to dip a legislative toe or two in the muddied waters of pharmaceutical supply regulation. And the channel remains unsecured.

Meanwhile, healthcare consumers remain in ignorant risk—and may continue so, unless Harbin’s worst fears come true and consumers are painfully enlightened by a cataclysm of counterfeits. Woe to industry and government alike if losing consumer trust is what it takes to secure the U.S. pharmaceutical supply channel. Better would be an industry initiative that openly acknowledges all the risks and adjusts standard practices to mitigate the risks openly, effectively—and voluntarily. FFF’s model could be the most effective and least painful solution: from the manufacturer to the ADR to the healthcare provider.

As Israel commented, “It’s in the best interest of industry that American consumers have confidence in their products.” ■

Note: Research assistance was provided by Zachary Pugh.

This article is adapted from an article in Pharmaceutical Commerce, the July/August 2007 issue.

Everyone Has a Story, and This Is the Mothers'

By Carol K. Miletti

This is a story of hope and fear, desperation and pain, guilt and humiliation—with a dash of optimism.

No, this is not a storyline for a soap opera. This is an account of the commonalities in the everyday lives of mothers with primary immune deficiency diseases (PIDDs), struggling to meet the health demands of their own bodies and those of their PIDD kids.

Anyone who has PIDD knows how challenging it can be to lead a normal life. What happens when you have children who have the same disease? Your life becomes a constant struggle, a balancing act. Do you take care of yourself or your kids first? If, like a typical mother, your kids come first, that doesn't leave much energy for you to care for yourself.

This dilemma is not the only thing these mothers have in common. Many find they lack a social life.

"Social life? What social life?" says Christine, a mother with PIDD whose daughter, Heather, also has the disease.

Mothers with PIDD and their children are often treated like hypochondriacs by family, friends and doctors before being properly diagnosed. Their previous social circles often fall to the wayside as the mothers focus on finding out what's wrong with them and their offspring. And the challenging path toward the PIDD diagnosis often results in huge financial problems and insurance headaches.

"My medical records over the last three years would fill a wheelbarrow," says Susan, who was diagnosed with PIDD following the birth of her daughter, Kathleen, who also has PIDD.

Moms who are sick lack energy and experience high pain levels while having to struggle to care for their kids. What happens to the family dynamics when one or more of their children are also ill? What about the jealousy that occurs when the sick child gets more attention than the healthy child? How do sick mothers manage all of this?

Some mothers feel guilty about passing the disease on to their kids. They also struggle with the decision to have additional children. And let's not forget about the men. Fathers bear a great deal of the burden: They often work longer hours to pay for the mounting healthcare costs,

pitch in with additional household chores and help the family stay together through the ups and downs of multiple infections, surgeries, depression and the highs that go with periods of wellness.

Carissa is no stranger to this hectic life. She has four boys, ages 2 to 10, who all have X-linked agammaglobulinemia (XLA). Because of their schedule of infusions, hospital trips, illnesses and doctor visits, Carissa has chosen to home-school her four boys. She says they "hit the jackpot" when all four were diagnosed. Despite her sense of humor, she struggles with the knowledge that she passed the gene to her sons, and she fears that they won't have good health insurance in the future. "The hardest part is the uncertainty of what might happen. I have to take it day by day and thank God every day for active little boys. My boys are lucky because they all have it and it is very normal for them."

Suzanne has two kids. She and her daughter both have PIDD. Her son, who is healthy, doesn't really understand PIDD. He often becomes "jealous with the extra attention Jacqui gets when sick or when having treatment," Suzanne says, adding that she and Jacqui face "daily challenges of fatigue, joint pain and regular infections." They are searching for a physician who will treat them with immune globulin on a regular basis, rather than every six months when their IgG levels get too low. "It is so frustrating and a real battle," says Suzanne.

Sheryl is another mother who knows what it's like to lead a PIDD life. Although she was not diagnosed until age 45, she has been sick her entire life. She spent the years leading up to her PIDD diagnosis being misdiagnosed with various diseases and maladies. Her youngest son, Shane, who also has PIDD, was diagnosed immediately because he had so many infections as an infant. "One of my kids expects the PIDD to go away eventually. Not happening," says Sheryl. "I feel like life goes by, energy is scarce... I can never catch up."

The hardest part for her family is realizing that this is a permanent condition with no cure. But she is very proud of her son and the way he manages his illness. "When he was diagnosed, he took it as just another thing to add to



his life." Now, he is always looking out for her. Parent and child—together they suffer, together they comfort.

Christine says she "has almost totally forgotten what healthy feels like." She doesn't feel well and has little energy most of the time. Luckily, her daughter is doing very well with her treatment. "The treatments have been a miracle for her," says Christine. "When Heather started her treatments she got better right away, and she has never been back in the hospital for sickness since." Although Christine has not had the good fortune her daughter has had with treatments, she notes that Heather shows her something new every day about patience and persistence.

The hardest thing about PIDD is one minute you're healthy, and the next minute you're down, and there isn't anything you can do about it. Christine thinks most people take for granted the little things that many PIDD patients can't do: "Going to crowded places and being around germs, touching a doorknob, allergy season, etc. I feel like we are somewhat trapped in our own little world."

Susan has had PIDD for nearly three years, and Susan's daughter, Kathleen, age 3, has recently been diagnosed with PIDD. Susan feels lousy most of the time with aches from rheumatic disorders, fatigue and nausea "from all of the pills and bills...I wish upon no one what I have lived through with this illness."

While other people plan their vacations, Susan says, "we hope we will have enough to pay rising health insurance premiums and medical bills that we know will last a lifetime... [It's] an endless, exhausting uphill climb with no water fountains or scenic vistas along the way, only the fond friendships of others with PIDD who lend their shoulders for support."

Susan says her short-term challenge is finding the physical capability to care for Kathleen. "Staying alive to enjoy my child and watch her grow up" is her longer term goal, she says.

With their stories often echoing one another, these mothers live their lives for their children and themselves. Together they share the challenges, uphill battles, insurance nightmares, frustrations and fears—and the helping hands of other PIDD patients reaching out, a gesture that is priceless. ■



You Need Help; I Want to Help Why Doesn't It Feel Good?

The Barriers to Effective Support

By Lauren Gerstmann, MPH

Chronic illness wears you out physically, mentally and emotionally. It takes its toll on caregivers, too. So how do you cope? The literature tells us patients and caregivers fare better when they are supported by friends and family, when they have a social support network.

Although most of us have family and friends out there who have the capacity to provide support, sometimes they just don't come through for us.

Usually, people want to help, but sometimes they just don't know what to do.

According to Benjamin Karney, a professor of social psychology at University of California Los Angeles, there is often a disconnect between your feeling supported and what people are doing to offer support. When you have been to your fifth doctor appointment in a week or when you have just realized that a new wonder drug has long-term side effects, it can be painful and confusing to call a friend who wants to chat about her bad day in the office. Even when people try to help, you may not feel supported because they may not be doing things that effectively support you, and this doesn't feel good to either of you.

Support Influences Health

There's a lot of evidence that support does influence physical health (e.g., blood pressure, cortisol levels, tumor growth) and psychological health (e.g., depression, anxiety,

self-efficacy). For example, partner support has been linked to depression vulnerability such that more support decreases vulnerability to depression and a lack of support increases vulnerability. There is also evidence of the importance of support for relationship satisfaction. For example, spouses reporting higher levels of partner support are more satisfied with their marriages than those reporting lower levels of support, and spouses often identify lack of partner support as a major reason for relationship dissatisfaction and dissolution.

What makes support effective? How do you accomplish the goal of making someone feel supported?

In considering effective support, an important distinction can be drawn between the *quantity* of support and the *quality* or *adequacy* of that support. Just as the amount of support influences physical and mental well-being, the effectiveness of support also contributes to individual well-being. Because not all support provided may be welcomed by the recipient, one person may believe he or she is providing a great deal of support whereas the other person perceives he or she is receiving little support.

Studies comparing the quantity of support with the quality of support across relationships have found both to be important contributors to one's physical health. For example, greater quantity of support, as measured by greater network size, is associated with higher levels of self-efficacy concerning pain and symptom management among women with fibromyalgia, whereas greater perceived quality of

support was associated with lower levels of depression, helplessness, and mood disturbance, higher levels of self-efficacy for function and symptom management, and greater overall psychological well-being. In another study, greater satisfaction with support was associated with lower cortisol responses and lower blood pressure.

For some people, less frequent support may actually be preferred. People have unique coping styles or dispositions. If an individual is not receiving the type of support that matches his or her preferred coping style (or is not receiving enough of that type of support), the result may be negative. For instance, the provision of undesired support may lead support recipients to view the support provider as insensitive or patronizing, especially if support is in the form of unwanted advice-giving. Support recipients may also experience feelings of guilt if they do not embrace the undesired support provided by another.

What Can Go Wrong

Some people may at times feel pressured to offer support, but if they do not know how to do so effectively, the pressure can lead to bad feelings. Then the provider may blame the person he or she is attempting to help: "I tried to support you, but you did not accept my support. It is your fault you do not feel supported."

Also, it is threatening to others when bad things happen to good people. People want to feel safe, so if they observe someone suffering from hard times or illness, it is tempting to look for a reason that person has been targeted. Out of self-protection, they may rationalize that "if misfortune happens for a reason and I am a good person, it won't happen to me!"

Undoubtedly, self-protective impulses can compromise the ability of a provider to offer adequate support. Dr. Karney says that researchers have determined several ways in which support might break down (see Figure 1).

The Just World Hypothesis

If observers are worried that they might experience the same problem as the person suffering, they might conclude that the other person has self-inflicted the suffering. We tend not to want to help people who "get what they deserve." In chronic illness, this may underlie the attitude that "you are overreacting" (see Zara's Story). In other words, someone in your support network who may see only snapshots and not the whole picture of your life might conclude that you are not really as sick as you think you are. Therefore, you don't really need help. This person may believe that if you stop overreacting, you will no longer have a problem and, consequently, not need support. In some cases, this may play into unexpected reactions and lack of responsiveness from physicians.

Fundamental Attribution Error

There is a general bias toward overestimating the control people have over their own actions or behavior and toward underestimating external influences or circumstances. This becomes a problem, for example, if someone comes home to a partner in a bad mood. The tendency is to say, "Why are you being so grumpy? What is wrong with you?" It takes increased effort to look beyond the bad mood and ask "What happened today that put you in a bad mood?"

Compassion Fatigue

Well-meaning people who want to help can become fatigued or tired of helping after offering long-term care. They may then become indifferent or look for ways to "let themselves off the hook." This fatigue can affect nurses, people who work with the chronically ill, and unpaid caregivers, such as family members. One mom told me that her loved ones couldn't keep up the effort to help her with her child; they simply became unavailable. "When they stop, they stop for good," she said. "Indifference is the worst thing." ➤

Figure 1. Issues that can compromise social support



Support Mismatch

There may be a mismatch between the type of support offered and the type of support needed. This can make the person in need feel unsupported and the provider feel unsuccessful. Psychologists speak of several types of support that can be broadly separated into two categories: 1) instrumental support, defined by active help (like buying groceries or cleaning the house) and 2) emotional support, defined as validation and sympathy. If you just need someone to listen, or tell you that they love you and think well of you, but that person wants to help you by taking you out for dinner, you may feel unheard and they may feel unappreciated.

Ineffective Request for Support

This is related to the support mismatch problem. Sometimes people do not know how to effectively ask for the kind of help that they need. For example, if you ask for support and are then critical of the support you receive, the person offering support may not want to try again. Once you express a specific need, it is not so helpful to instruct people how they should fulfill it. For instance, you might say, "I need you to take care of the dishes," or "I just need you to listen," and then let your caregiver determine how he or she can best do that for you. Although it may be hard to ask for help effectively when you are embarrassed by the request or when you do not want to feel beholden, people are usually happy to know specifically how they can help you.

Different Types of Support

Another important issue concerns the different types of support that can be provided. Researchers and clinicians typically consider there to be four types of support:

1. Emotional support (e.g., providing reassurance, love and affection)
2. Informational support (e.g., providing information and advice)
3. Esteem support (e.g., validation or showing confidence in the partner's abilities)
4. Instrumental or tangible support (e.g., providing direct or indirect assistance in solving the problem).

Sometimes a fifth type of support is included:

5. Network support (e.g., encouraging the partner to make use of social resources, such as family and

friends). However, network support has more to do with the size and/or availability of one's support network rather than a particular type of support.



The Art of Asking for Support

Being able to ask for and accept support is as much a skill as being able to provide support. Although most people focus on the effects of providing support, there is evidence that the ways in which a person asks for and accepts (or receives) that support also influence physical and psychological health. In one study, women's ability to provide support positively affected their own health status more than their ability to receive support, as indicated by fewer absences from work due to illness. However, among men, receiving more support predicted fewer absences than giving more support.

People typically don't think about asking for support and accepting support as skills. One possible reason for this oversight is that people usually conceptualize the support provider as having an active role whereas the person requesting or on the receiving end of the support is often perceived as being a passive recipient.

It is important to understand the role that denial plays in these issues. While denial in a situation such as Zara's can be toxic, in many cases it is a simple coping mechanism. If two parents are caring for a sick child, they may choose to divide responsibility so that one parent is primarily responsible for the child's health and the other parent is responsible for paying the bills. The parent paying the bills will have to be able to focus on the workplace and fulfill job responsibilities without being sleep-deprived or distracted by what



is happening at home. Mild denial, in that case, might even be functional. But it can still be hard on the parent bearing the brunt of the medical situation at home.

These factors will play into every relationship. Failure of social support occurs on a continuum. In a healthy relationship, the level of social support can vary throughout a relationship. In an unhealthy relationship, social support can fail dramatically. In these situations, the only way to get what you need is to get creative. But, in a healthy relationship, effective communication and nurturing might provide some of the answers.

Real Life Answers

Caregivers are portrayed in the media as indefatigable providers—heroes who operate without needing anything for themselves. This is not reality. Trying to care completely for another person's needs, putting them first 100 percent of the time, can lead to compassion fatigue. It is critical that the caregiver be refreshed. This can be a very frustrating message when you are caring for someone with a chronic illness, because taking time off may not be an option. But, if you acknowledge this need, even though instrumental support may not be possible, emotional support may fill some of this gap. Successful support, even successful emotional support, is concrete, but not prescriptive. In other words, it helps if support providers make specific offers that don't sound like orders, such as "Would you like me to make some calls for you?" Or, if you are the one needing respite, it helps to make specific requests such as "Could you watch Sara so I can rest for an hour?" This kind of careful effort is difficult, especially when you have many demands on your time and emotions.

For example, when Kristin's son, Conner, began showing the signs of a significant immune deficiency, she and her husband felt isolated. But they shored each other up and turned to their community for help. Once they began to reach out, their friends, family and church came through with an incredible show of support (see Kristen's Story). Because of her experience, Kristin developed some specific suggestions for offering instrumental help and emotional support (see Kristin's Tips). Although designed with an immune deficient child in mind, these suggestions generalize well to any chronic illness.

Improving your ability to ask for support effectively can help prevent support mismatch. And, being aware of and preventing compassion fatigue by getting some respite (even if just an emotional break) is important. But it is also important to try to prevent fundamental attribution error. Simply

being aware of our tendency toward bias may be the best way to accomplish this. When your friend starts in about her bad day at the office, try to remember that her stress is impacting her ability to listen to you. Most people we rely on for support are already dealing with their own stressors, and their circumstances matter, too.

Zara's story shows that, for reasons beyond your control, there may be times when your closest loved ones simply are unable to offer support. In these situations, you may need to seek out other forms of respite. For Zara, solace came from her community activities, activism and her faith.

Easier said than done, finding respite requires a lot of self-awareness and good communication. It is usually too simple to say that there is no support out there. People generally care and want to give support, but they encounter the significant barriers discussed above. People's reactions are a function of what they encounter and what emotional history they bring to that encounter. One mom says, "You can move toward pain and address it in a constructive manner with those you trust. Or you can move away from it and tell people that you are 'fine' when you are not. Moving away from pain may lead to suffering in isolation."

Being aware of the factors that inhibit support, anticipating those factors we can control, and understanding those that we cannot control may help us feel less alone. Ultimately, sometimes the best method for determining how to provide or receive the most effective support is to ask: If you want support, ask for it; if you want to offer support, ask what would help.

Zara's Story

Zara was a healthy woman when she married her boyfriend of 17 years. Although they had had their ups and downs, he had recently been diagnosed with multiple sclerosis, and she wanted to take care of him.

The reality has proven quite different.

Zara's husband has remained fairly healthy on his treatment, but after 18 months of marriage, Zara developed polymyositis, a condition so debilitating that at times she has trouble getting up from her chair. Zara takes a lot of medication to maintain her physical function, including steroids, which have caused her to gain weight. Rather than supporting her, however, her husband retreats into silence. "He will stop talking at the drop of a hat, maybe after I ... get upset with him for not doing something ➤

that he could easily have done, it is hard to say but it has been more and more since being diagnosed.”

It almost seems as if Zara’s husband equates silence with stoicism. He doesn’t talk about his own illness either. When Zara tried to share a small triumph with him (she found a way to put on her socks), he commented, “Oh quit feeling so sorry for yourself.” Zara dissolved into tears and then resolved to look elsewhere for support. Beyond stoicism, Zara’s husband seems to resent her illness. When Zara tried to ask him why, he angrily responded, “Bothered, bothered, I’m not bothered about it. I don’t understand this medication thing.” By this, he confessed he meant that he was upset by Zara’s weight gain—the only part of her illness that seems to register with him.

Today, Zara has accepted her situation. She has developed a significant online support community through a blog she maintains and also through The Myositis Association support group. She even logs onto multiple sclerosis support sites to gain insight into her husband’s illness.

Kristin’s Story

Kristin first began to realize that there was a serious problem with her son, Conner, when he was 9 years old. Conner is a triplet who was born prematurely.¹ He and his siblings had always had some illnesses, but it began to seem that Conner was much sicker. Chris, Kristin’s husband, would tease Kristin when she panicked over Conner’s frequent colds. But when Conner had trouble breathing after one of his colds and was hospitalized, it was time to treat the problem seriously.

Chris began joining Conner and Kristin at doctor appointments. At first these were a frustrating experience, because doctors didn’t seem to take the situation seriously. They switched pediatricians to get Conner better care and referrals to specialists, but even the immunologist they saw was not sure how serious Conner’s problem was. Later, when Conner was diagnosed with NEMO (a serious primary immune deficiency), the doctors became more supportive, and Chris also completely understood and supported his medical care. Kristin and Chris were almost relieved to have a diagnosis, because they felt that they could start concrete action toward finding a cure.

Kristin stays home and spends more time caring for Conner than Chris, who works full time. As a result, she feels hyper-alert whenever Conner is sick. Chris is concerned

about Conner’s long-term health, but is not as upset by the roadblocks on the way. The important thing is that Kristin and Chris understand each other’s fears and coping mechanisms, and they successfully support each other. When Chris is too tired or overwhelmed to talk about Conner’s health, he takes the kids and sends Kristin off to have dinner with her friends. Chris is a very hands-on dad, and he plays and spends a lot of time with the kids when he is not working. As a result, Kristin gets some respite, and she feels appreciated. Kristin also makes sure that Chris has time away from the family to play softball with his friends and to unwind.

At first, Conner’s extended family was not very involved. They did not seem to want to talk about Conner’s health problems. They also seemed to blame some of Conner’s health problems on his parents, implying that he wouldn’t be sick so frequently if his parents took better care of him. Kristin and Chris felt very alone. Fortunately, they were able to talk to each other about it, but they did not know how to reach out for help until Kristin confided in her best friend, who began organizing a fundraiser when she learned that Conner would need a bone marrow transplant. Through raising funds, she raised awareness. Soon everyone who had been unable to talk about Conner’s illness knew how they could help. Friends and family contributed time and money, and were also able to be more emotionally involved. Kristin realized that they had wanted to help all along, but had not known how.

The family’s church was also a great source of support. The pastor helped with fundraising and organized significant renovations to the family home, which made it safer for Conner. Church members donated money to remove carpet and put in wood floors to ease Conner’s breathing problems. The church continues to raise money for Conner’s medical care and has been very active in supporting his upcoming transplant.

Even Conner’s school has pitched in. At first, Conner had trouble at school because the children, teacher, and staff did not understand his illness. But Chris’ sister asked the teachers to pass out fliers that explained Conner’s situation and how to support the family. Not only did the fliers help Conner and his parents, they also helped Conner’s brothers and sister, who attend the same school. Now that people understand what they are experiencing at home, the siblings are also receiving more support. ■

¹ For more about Conner, please see “Bone Marrow Transplant: The Search for a Cure” in the August-September 2007 issue of *IG Living*.

Kristin's Tips for Supporting Families With Primary Immune Disorders

Living with a primary immune disorder may leave the family dealing with frequent hospitalizations and clinic visits, as well as serious financial difficulties. Some days may be overwhelming and can lead to feelings of loneliness and frustration for everyone.

Here are everyday ways you can help your friends or loved ones cope with managing their illness:

- Let the family know that you care about them and you want to help. Don't avoid them when you don't know what to do or say; this will make them feel as though you are indifferent to their situation. Make a point to check in with the family on a regular basis. Your support is invaluable in this life-long situation!
 - Don't wait for the family to call you for assistance; they may not know how to ask for help. When necessary, make specific offers, such as mowing the lawn, baby-sitting, bringing dinner, picking up groceries, providing transportation, etc.
 - Be available to listen and learn about the family's medical issues, but reserve comments that may suggest you question the diagnosis or minimize the seriousness of the illness.
 - Always be considerate of the family's need to avoid germs by washing hands frequently during visits and staying away from the family when you are ill.
 - Continue to invite the family to do fun things, and ask how you can make it work with their related health needs. They may not always be able to participate, but will appreciate the offer.
- Keep in mind that when the family says they are doing fine, they may be trying to hide their fears and frustrations. Continue to let them know that you are there for them.

Here are ways you can give them help during hospitalizations:
 - When possible, go and sit with the patient or parent(s) in the hospital. Even routine hospitalizations can be lonely and overwhelming at times. Just listening and providing empathy is very helpful.
 - Help coordinate care for the siblings at home, if necessary. Don't forget that they may be scared and confused. Make sure they feel important too by being available for them to discuss their concerns, scheduling fun activities and sending cards or small gifts.
 - Offer gifts for those who are hospitalized. Children in the hospital might enjoy small treats like stickers, coloring books or puzzles. For teens, consider offering to arrange transportation for their friends to visit at the hospital.
 - For the patient or parent, consider bringing gift certificates for restaurants and video rental stores near the hospital, as well as magazines or favorite snacks. Due to risk of infection for the patient, avoid bringing or sending live flowers, plants or fruits without permission.

For More Information

For respite care resources near you, visit the ARCH National Respite Network at www.archrespite.org.

To learn about primary immune deficiency disorders, visit www.primaryimmune.org and www.jmfworld.org.

A Typical Superman

By Mark T. Haggard



I've heard "typical" used to describe the siblings of a child with a disability. My oldest boy, Calvin, is the typical child in our family, but that term doesn't do him justice. He actually goes far beyond being typical.

I spend so much time telling people about Caleb and Molly, Calvin's siblings, and their immunological issues that Calvin sometimes gets kicked to the curb. But he has learned to be gracious and humble of heart and to understand that attention directed to his family and friends is more important than that directed to him.

Like many fathers, I put my boys into sports early on. I wanted to know if they were scholarship material or if I needed to start saving for college. The first sport I got them into was soccer.

"I like playing goalie," Calvin said after a game. "That's the position where you take the ball out of the net and hand it to the referee." When his brother, Caleb, played goalie, he was not so much interested in stopping the other team's shots as he was in grabbing at the net

and yelling, "I'm Spiderman."

This past winter Calvin played basketball for the first time. At first he was afraid to put the ball in the air. I pulled him aside and reminded him that the only way his team could score was if the ball went through the basket. The next week he recorded the first two points of his career.

"Dad, Dad!" he exclaimed with a mammoth smile after the game.

"How does it feel, son?"

"We won. Colton scored, like, eight points, and Ryan scored six, and I think Timmy had six!"

"Calvin," I replied fishing for some conceit on his part, "I want to know how you scored your points?"

It was no use. Living with a younger brother and sister with a chronic illness has caused an altering of the synapses in Calvin's typical emergent brain. Because Calvin helps set up infusion supplies on Caleb and Molly's treatment days, he understands what it means to be a team player. Doctor's appointments that don't include a review of his



relatively short medical history have taught Calvin to think of others before himself. Calvin sees that his contribution to the final victory is irrelevant when compared to his team's success.

This past spring, my boys played on the same Little League team. This was their first experience wearing protective cups. During one game, I saw all of my—uh, their—scholarship money vanish as they sat in the dugout and hit themselves in their crotches with their fists.

"That's hurting my hand," Calvin exclaimed rubbing his knuckles.

"Let's try a baseball."

"No, a bat!"

"Yeah!"

Soon Calvin and Caleb were hitting each other in the crotch with baseball bats. "I can wear this to school tomorrow. I can be like Superman."

At the end of the season, my boys' team was in the championship game. Sadly, Caleb had to be in an out-of-state hospital on the same day, but Calvin kept him

updated with phone calls from the dugout. Then he gave him the best phone call:

"Caleb, we won!"

"That's cool! How'd you do?"

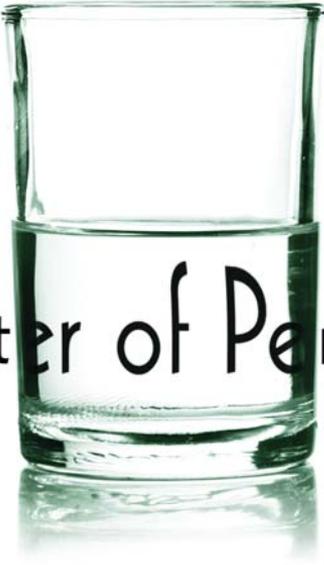
"We beat the Mariners, 14 to 5. No one beat the Mariners all year."

"Calvin, how many hits did you get?"

"Oh, I had a triple and two doubles. But that's not important. We won! We're the champions! I'll have a T-shirt for you when you get home."

As an athlete, Calvin can hang with other boys his age and have fun and success doing it. In one recent game, Calvin smoked a game-ending home run over the left fielder's head. But I am more proud of the fact that my typical child is becoming an atypical young man, filled with compassion and humility and seeking to build up others rather than himself.

Calvin doesn't need to hit home runs or wear a protective cup to be a Superman. He already is. He wouldn't tell you that, though. ■



A Matter of Perspective

By Dayna Fladhammer

Recently, I began seeing stickers and T-shirts all over the place that say, "Life is good." There is something about the simplicity of this that struck a chord with me. It's true, life really is good. Even with chronic illness and infusions and all that this disease entails, life is good.

The simplicity of that statement stuck with me, and I ended up buying a sweet, pink bag with that same message imprinted across it. I didn't actually need a new bag; I bought it more as a daily reminder to myself that life is good, even with the trials we've encountered.

I need that reminder more than I'd like to admit. I actually tend toward being a pessimist, so it's a constant battle for me to stay optimistic.

In the beginning, when the kids were first being diagnosed, I used to wonder why me, why them? I fell into the depths of despair. There was a time when I felt as though my feet were stuck in cement and I'd never be able to walk one more single step forward. I've fought that pessimism as my children's health has improved on IVIG. So now, I've been carrying that "Life is good" bag for the last couple of months, and nowhere have I received more comments than at the Immune Deficiency Foundation Conference held in St. Louis, Mo., in July.

If I was asked once, I was asked 100 times about the bag and where I got it. People loved it. It amazed me that at a conference filled with people who have so much on their plates, who have overcome so many obstacles or who still face so many obstacles, that "Life is good" would resonate so strongly.

Maybe that's part of the appeal. Maybe those of us who have had trials, or have experienced great adversity, appreciate life that much more. We've learned our own attitudes are half the battle. So, I've adopted "Life is good" as one of my two family themes.

I realized even more the deep importance of attitude when I began reading the "Express Yourself" wall provided by IVIG manufacturer Baxter at the conference. This wall, with little more than blank paper and markers, slowly evolved into a meeting place where everyone from patients to caregivers could express their deep and not-so-deep thoughts anonymously or, throwing caution to the wind, let the conference know exactly who they are and how they feel.

It was there, at this wall, that I found the second theme for our family. I read a message from 17-year-old Meredith from Minnesota. This teen with PIDD expressed in eight words the attitude I want my children to have for the rest of their lives. Her words, surrounded by a guitar engulfed in flames, read, "I will not let this disease beat me."

That's it, right there. That's what I want for my children. That's the attitude I want to impart to them. Her words so strongly resonated with me they renewed my hope for my children and made me proud of a teenager who is not even my own. I knew right then that we will not let this disease beat our family!

We will not give in to the stress of dealing with chronic illness in daily life; my husband and I will not succumb to the pressures of parenting children with such depth to their needs; we will not allow the pressure we feel to fracture the relationship we have with each other or our need to care for ourselves; and we will not let this disease limit how we help our children plan for their future or how we plan for our own.

I may not be able to control what happens around us or to us, but I can and will change my perspective, improve my attitude and remember that it all boils down to two things: Life is good, because I will not let this disease beat me. ■

Resource Directory

Guillain-Barré Syndrome (GBS)

Websites and Chat Rooms

- The GBS/CIDP Foundation International, www.gbsfi.com, has 23,000 members in 160 chapters on five continents. 610-667-0131
- 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.
- Miller Fisher syndrome, considered to be a variant of GBS, is explained on the National Institute of Neurological Disorders and Stroke, NINDS Miller Fisher Syndrome Information Page: www.ninds.nih.gov/disorders/miller_fisher/miller_fisher.htm.

Online Pamphlets

- The National Institute of Neurological Disorders and Stroke has a GBS Fact Sheet at www.ninds.nih.gov/disorders/gbs/detail_gbs.htm.
- The Mayo Clinic has an overview of Guillain-Barré syndrome at www.mayoclinic.com/health/guillain-barre-syndrome/DS00413.
- The National Institute of Neurological Disorders and Stroke has an information page about CIDP: www.ninds.nih.gov/disorders/cidp/cidp.htm.

Online Peer Support

- GBS & CIDP Discussion Forum – UK Bulletin Board – For Ireland and England www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi
- GBS Support Group and Chat Room, UK <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

Books and Articles

- “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.
- “Bed Number Ten,” by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
- “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.
- “No Laughing Matter,” by Joseph Heller (the best-selling author of Catch-22), who teamed up with Speed Vogel, his best friend, to describe Heller’s battle with and triumph over GBS.

ITP (Idiopathic Thrombocytopenic Purpura)

Websites

- ITP Support Association, UK: www.itpsupport.org.uk
- Platelet Disorder Support Association: www.ITPpeople.com
87-PLATELET (877-528-3538) or 301-770-6636

Online References

- Idiopathic thrombocytopenic purpura http://en.wikipedia.org/wiki/Idiopathic_thrombocytopenic_purpura
- Idiopathic Thrombocytopenic Purpura: Michael A. Silverman, MD www.emedicine.com/EMERG/topic282.htm

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

Kawasaki Disease

Websites

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

Mitochondrial Disease

Websites

- United Mitochondrial Disease Foundation promotes research and education for the diagnosis, treatment and cure of mitochondrial disorders and provides support to affected individuals and families. www.umdf.org
- The Cleveland Clinic website provides many articles when searched by the topic, “mitochondrial disease.” www.clevelandclinic.org/health
- The National Institute of Neurological Disorders and Stroke provides an informative Mitochondrial Myopathies Information Page. www.ninds.nih.gov/disorders/mitochondrial_myopathy/mitochondrial_myopathy.htm

Multiple Sclerosis (MS)

Websites and Chat Rooms

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

Online Peer Support

- Friends with MS: <http://friendswithms.com>
Forum: <http://health.groups.yahoo.com/group/FriendsWithMS>
- My MSViews: www.mymviews.org
Forum: http://health.groups.yahoo.com/group/MSViews_Multiple_Sclerosis
- MS Support Group: <http://health.groups.yahoo.com/group/mscured>

- The MS Carousel—A Place to Meet With People Who Understand MS!
<http://health.groups.yahoo.com/group/themscarousel>

Myasthenia Gravis (MG)

Websites and Chat Rooms

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

Online Peer Support

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

Myositis

Websites

 <p>THE MYOSITIS ASSOCIATION</p>	<p>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</p>
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- 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>
- 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>
- Johns Hopkins Myositis Center is a new patient treatment center that brings the expertise of rheumatologists and neurologists into a single clinic for patients with inflammatory (autoimmune) and toxic (drug induced) muscle conditions.
www.hopkinsmedicine.org/rheumatology/clinics/myositis_center.html

Online Peer Support

- Juvenile Myositis Family Support Network:
www.curejm.com/family_support/index.htm
- Myositis Association Community Forum: www.myositis.org
- Myositis Support Group: www.myositisupportgroup.org
- Myositis Support Group UK: www.myositis.org.uk
- Yahoo Myositis Support Group Discussion Board:
<http://health.groups.yahoo.com/group/OurMyositis>
- The California Myositis Symposium held in 2005 was captured on DVD. It contains information about polymyositis, dermatomyositis and inclusion body

myositis, including doctors' discussions and detailed slides and explanations of muscle biopsies, skin rash, and tools used to diagnose these diseases. Other presentations offer valuable lessons in maintaining a positive attitude, exercises for physical therapy and innovative tools to aid in everyday activities. The DVD is available at no charge by sending an email to Richard Gay at rgay@socal.rr.com.

Books and Articles

- "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.
- "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.
- "Living With Myositis," edited by Jenny Fenton, is an accessible, realistic and sympathetic guide to facts, feelings and future hopes.
- "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.
- "Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers" is an indispensable resource for families of children with myositis and their healthcare teams is available at www.myositis.org.
- "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.

Pemphigus and Pemphigoid

Websites

- The International Pemphigus and Pemphigoid Foundation provides information and support to people living with the autoimmune diseases. www.pemphigus.org
- Information from the National Institutes of Health:
www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm
www.nlm.nih.gov/medlineplus/ency/article/000882.htm
- Rare disease report: <http://rarediseases.about.com/od/rarediseases/p/lepemphigus05.htm>

Peripheral Neuropathy (PN)

Websites

 <p>The Neuropathy Association</p>	<p>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</p>
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- To learn about PN, how it is classified, the symptoms, causes and treatments, see the Peripheral Neuropathy Fact Sheet available at www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm.
- The Neuropathy Action Foundation, at www.neuropathyaction.org, educates, empowers and informs patients and physicians about neuropathy.

Support Groups

- Click on the Member Services tab of the website, www.neuropathy.org, for listings of support groups across the nation.

Online Peer Support

- Calgary Neuropathy Support Group: www.calgarypnrs.org/index.htm
- 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>

Books and Articles

- “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.
- “Medifocus Guide to Peripheral Neuropathy,” is a guide to current and relevant PN research, organized into categories for easy reading.
- “Numb Toes and Aching Soles,” by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
- “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.
- “Nutrients for Neuropathy,” by John Senneff, the third in the Numb Toes series, is focused exclusively on nutrient supplementation as a means for managing PN.

Primary Immune Deficiency Disease (PIDD)

Websites and Chat Rooms

 <p>IMMUNE DEFICIENCY FOUNDATION</p>	<p>The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is dedicated to improving the diagnosis and treatment of PIDD through research and education. 800-296-4433</p>
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	<p>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</p>
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- 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.”
- 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.
- The Michigan Immunodeficiency Foundation, www.midf.org, seeks to improve the quality of life for Michigan residents affected by PIDD.
- The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PIDD patients.
- To connect to a PIDD message board, go to www.info4pi.org.
- To chat with peers on IDF’s Forum, go to www.primaryimmune.org/forums/forum_intro.htm.
- Chat with parents of children affected by primary immune deficiency at <http://health.groups.yahoo.com/group/PedPID>.
- Chat with peers with PIDD at <http://health.groups.yahoo.com/group/PIDsupport>.

- A group of family and friends of patients with primary immune deficiencies maintains a nonprofit network in the New England area: www.nepin.org
- Baxter’s website, www.immunedisease.com, offers in-depth information on immunology, PIDD and treatment with intravenous immune globulin. Click on “European” to see SCIG information.

Online Pamphlets and Education

- Go to the National Institute of Allergy and Infectious Diseases site at www.niaid.nih.gov and search for “primary immune deficiency.”
- “Understanding the Immune System: How It Works,” by the U.S. Department of Health and Human Services, is found at www.niaid.nih.gov/publications/immune/the_immune_system.pdf
- “NIAID Initiative Addresses Primary Immune Deficiency Diseases by National Institute of Allergy and Infectious Diseases” is located at <http://www3.niaid.nih.gov/news/newsreleases/2003/pirc.htm>
- The “Immunodeficiency in Pediatrics” program (PREP®) Audio series is a new pediatrician education program that can be obtained by contacting the American Academy of Pediatrics at 866-843-2271 or visiting www.prepaudio.org.

Online Peer Support

- 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
- Jeffrey Modell Foundation Message Board: www.info4pi.org

Books and Articles

- “21st Century Complete Medical Guide to Primary Immune Deficiency, Severe Combined Immunodeficiency (SCID), Chronic Granulomatous Disease (CGD), for Patients and Physicians,” by PM Medical Health News, contains federal government clinical data and practical information for patients and physicians.

Stiff-Person Syndrome (SPS)

Websites

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

General Resources

Product Information

- Influenza and the influenza vaccine www.cdc.gov/flu or call 800-CDC-INFO (800-232-4636)

- IVIG Carimune NF www.carimune.com
- IVIG Flebogamma www.grifolsusa.com/flebogamma.htm
- IVIG Gammagard Liquid www.gammagardliquid.com
- IVIG Gammagard S/D
www.immunedisease.com/US/therapies/gammagard/index.html
- IVIG Gamunex www.gamunex.com
- IVIG Octagam www.octapharma.com/corporate/03_products_and_therapeutic_areas/01_immunoglobulin_product_line/03_octagam.php
- SCIG (subcutaneous immune globulin) Vivaglobin www.vivaglobin.com

Other Organizations

- Alliance for Plasma Therapies is a unified, powerful voice of patient organizations, healthcare providers and industry to advocate for fair access to plasma therapies. www.plasmaalliance.org
- For suggestions on how to deal with the medical and emotional impact of caring for an ill child, go to www.kidshhealth.org/parent/system/ill/seriously_ill.html.
- The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at www.nccqa.org.
- The nonprofit Patient Advocate Foundation, www.patientadvocate.org, seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274



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

- 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.
- For a pediatrician's guide to your child's health and safety, visit www.keepkidshealthy.com.
- 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.
- American Autoimmune Related Diseases Association (AARDA) www.aarda.org brings national focus to autoimmunity through research, education and patient services. 800-598-4668
- Band-Aides and Blackboards, www.lehman.cuny.edu/faculty/jfleitas/bandaides, started by a nurse working on her dissertation, focuses on children with chronic illness.

Education and Disability Resources

- Continuation of Health Coverage—Consolidated Omnibus Budget Reconciliation Act (COBRA): www.dol.gov/dol/topic/health-plans/cobra.htm
- 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.)
- IDEA 2004 Resources: www.ed.gov/policy/speced/guid/idea/idea2004.html
News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities.
- The National Disabilities Rights Network: www.ndrn.org. This website offers a search tool to find resources in your state to assist with school rights and advocacy.

- U.S. Department of Education Website: www.ed.gov. This website, a U.S. federal government website, offers a parents section that has a subsection titled "My Child's Special Needs" that can be most helpful.
- U.S. Department of Health and Human Services, Office of Civil Rights, www.hhs.gov/ocr/504.html, spells out your rights under Section 504 of the Rehabilitation Act.
- Wrightslaw: www.wrightslaw.com. Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities.
- The Americans with Disabilities Act of 1990
Provides protection for people with disabilities from certain types of discrimination and requires employers to provide some accommodations of the disability. For more information, visit www.usdoj.gov/crt/ada/adahom1.htm.

Additional Reading

- "Anatomy of an Illness," by Norman Cousins, is a best-seller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body's capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
- "A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed," by Linda Wilmschurst and Alan W. Brue, is available on Amazon.com.
- "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.
- "The Everyday Guide to Special Education Law," by Randy Chapman, Esq., makes the law accessible to parents so they can be more effective advocates for their children. Available at www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15.
- "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.
- "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.
- "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.
- "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.
- "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.
- "When You're Ill or Incapacitated" comprises one-half the booklet it shares with "When You're the Caregiver," both written by James E. Miller, suggesting 12 things to remember or do in each role.
- "YOU the Smart Patient: An Insider's Handbook for Getting the Best Treatment," by Michael F. Roizen, MD, and Mehmet C. Oz, MD, with the Joint Commission on Accreditation of Healthcare Organizations, shows you how to tackle such healthcare decisions as picking the best doctors and hospitals for you, knowing when to get a second opinion, and more.

IG Manufacturer Websites

- Baxter: www.baxter.com
- CSL Behring: www.cslbehring.com
- Grifols: www.grifolsusa.com
- Octapharma: www.octapharma.com
- Talecris: www.talecris.com

Pump and Infusion Sets Websites

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

Medical Research Studies

- Check out the official website for the National Institutes of Health patient recruitment program. This site provides summaries and criteria for studies as well as the ability to search for studies being conducted for a specific disease or disorder. <http://clinicalstudies.info.nih.gov>
- This website provides a wealth of information about clinical trials and volunteer participation. It gives you the ability to specify the disorder you are interested in, the location of the study, and the medication names or research protocols. www.centerwatch.com
- This site has a registration form to request that you be notified about recruitment for future studies. www.clinicaltrials.com
- WebMD has a service that matches volunteers with trials. There is an online questionnaire to complete and you will be notified via email of upcoming studies that match the criteria of your questionnaire. You can also search for specific studies. www.webmd.com

Food Allergies

- Allergic Disorders: Promoting Best Practice www.theallergyreport.com/reportindex.html
- American Partnership for Eosinophilic Disorders: www.apfed.org
- National Institutes of Health, National Institute of Allergy and Infectious Diseases (2004). Food Allergy: An Overview (NIH Publication No. 04-5518). www.niaid.nih.gov/publications/pdf/foodallergy.pdf
- Sicherer, S.H. (2006). "The Complete Peanut Allergy Handbook: Understanding and Managing Your Child's Food Allergies," Johns Hopkins Press.
- Food Allergy and Anaphylaxis Network: 800-929-4040 www.foodallergy.org
- World Allergy Organization: www.worldallergy.org

Nutrition and Food Safety

- American Board of Physician Nutrition Specialists: www.ipnec.org
- American Dietetic Association: www.eatright.org
- American Gastroenterological Association: www.gastro.org
- North American Society for Pediatric Gastroenterology Hepatology and Nutrition: www.naspgn.org/
- Bovine spongiform encephalopathy (BSE) www.aphis.usda.gov/newsroom/hot_issues/bse.shtml
- Childhood choking prevention: www.ific.org/publications/brochures/index.cfm
- American Academy of Allergy, Asthma & Immunology (AAAAI): www.aaaai.org Patient Information and Physician Referral Line: 800-822-2762
- The Food Allergy & Anaphylaxis Network: www.foodallergy.org 800-929-4040
- U. S. Food and Drug Administration, Center for Food Safety and Applied Nutrition www.cfsan.fda.gov Food Information Line (24 hours): 888-SAFEFOOD
- USDA Meat and Poultry Hotline: www.IsItDoneYet.gov 888-MPHotline 888-674-6854 · TTY: 800-256-7072
- Dietary Guidelines for Americans, 2005 Edition: www.health.gov/dietaryguidelines

- Drug Nutrient Interactions (MedlinePlus & the Physician Desk Reference): www.nlm.nih.gov/medlineplus/ or <http://www.pdrhealth.com>
- Electronic menu planner: <http://hp2010.nhlbihin.net/menuplanner/menu.cgi>
- Modified Food Pyramid for Older Adults (Tufts): <http://nutrition.tufts.edu/consumer/pyramid.html>
- The American Dietetic Association or to find a registered dietitian in your area: www.eatright.org or 800-877-1600
- USDA: MyPyramid personal nutrition tracker: www.mypyramid.gov

Nutrition Assistance Programs for the Elderly

- Community-based services can be located through the Eldercare Locator: www.eldercare.gov 800-677-1116.
- Nutrition, Aging, and Assistance: <http://nutritionandaging.fiu.edu>
- Meals on Wheels Association of America (MOWAA) provides home-delivered meals services to older adults, homebound, and at-risk individuals. For help, or to give a gift, go to: www.mowaa.org 703-548-5558

Reading Just for Kids

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

Working Caregivers

- Caregivers USA <http://caregivers-usa.org/db/index.html> Provides an index of local and state caregiver support services.
- Home Based Careers <http://edirectoryofhomebasedcareers.com/dir2.htm> Download an eDirectory of home based careers.
- Families USA www.familiesusa.org 202-628-3030 A nonprofit organization dedicated to the achievement of high-quality, affordable health and long-term care for all Americans. At www.familiesusa.org/resources/program-locator, they offer a program locator that will direct you to a local program to answer questions and assist you in obtaining health insurance. Programs may also be able to refer you to low-cost or free healthcare, including prescription drug assistance.
- Patient Advocate Foundation www.patientadvocate.org 800-532-5274 A national nonprofit organization that serves as an active liaison between the patient and his insurer, employer, and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to his diagnosis through case managers, doctors and attorneys. They offer a pharmaceutical co-pay assistance program to patients who qualify medically and financially.
- Work Options www.workoptions.com Templates and tips for writing a proposal to telecommute, work part time, job share, and/or switch to a compressed workweek schedule.

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

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