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63 for a Cure

Strengthening Ashley:
A Young Family Finds Hope
in IG Therapy

IG Reimbursement
How Did We Get Where
We Are Today?

A community service from FFF Enterprises and NuFACTOR Specialty Pharmacy

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About IG Living

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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.

Hospital-Acquired Infections: Should Medicare Pay?



The following editorial offers an opinion about a change in Medicare regulations that is addressed in this issue's reimbursement article, on page 26. The new CMS rule will result in denial of reimbursement to hospitals for certain medical errors and infections acquired by patients while in the hospital. Although, as the author writes, the CMS intent to reduce Medicare costs for preventable infections is laudable, the complexity of this issue intensifies for patients with immune impairments. Whether the new rule has the desired effect of improving patient care will not be known until the rule's implementation in October and the months that follow.

We encourage patients and providers to track this issue—and we'd like to hear your opinions! Send them to editor@igliving.com.

Medicare Non-Payment for Selected Medical Errors and Nosocomial Infection

Dennis Cada, PharmD, FASHP, FASCP
Editor-in-Chief, *Hospital Pharmacy*

According to new Medicare regulations, which become effective October 1, 2008, hospitals will no longer receive payments for costs associated with certain medical errors or specific hospital-acquired infections. The regulation may be viewed at: www.cms.hhs.gov/AcuteInpatientPPS/downloads/CMS-1533-FC.pdf. These new rules were designed to provide hospitals with an impetus to improve patient care and reduce cost.

Under rules adopted by the Centers for Medicare and Medicaid Services (CMS), payments to hospitals will be withheld for:

- catheter-associated urinary tract infection
- vascular catheter-associated infection
- mediastinal infection after coronary artery bypass graft surgery
- decubitus ulcer
- hospital-acquired injury, such as a fracture from a fall
- objects left in a patient during surgery
- air embolism
- blood incompatibility

To comply with the Deficit Reduction Act of 2005, CMS evaluated a number of serious, preventable, healthcare-acquired conditions and was charged to select at least two conditions that could reasonably be prevented through adherence to evidence-based guidelines, which otherwise

frequently resulted in a higher-paying secondary diagnosis at discharge. The above eight conditions were identified for non-payment. CMS will no longer reimburse for the additional costs associated with these conditions. In upcoming years, CMS intends to consider additional medical errors and hospital-acquired infections for nonpayment, which will decrease costs and improve care.

On face value, the concept is solid. Why should Medicare pay for misadventure? However, the concept of improving patient outcomes and medical accountability by reducing payments is not without detractors. All outcomes have a multifaceted cause. For example, a catheter-associated infection may have been caused by an infection acquired outside the hospital that only expressed itself after admission. There is also concern that establishing baseline conditions upon hospitalization may increase unnecessary testing procedures (e.g., all admits requiring a blood and urine culture).

These regulations include patient protections to prevent them from being billed if payment is withheld by Medicare. Additionally, a hospital should have the ability to appeal any non-coverage decision (e.g., any infection that may not have been preventable). It will be interesting to monitor both the patient and hospital protections built into the regulations.

The costs associated with medical misadventures and preventable errors are staggering; the intent of the CMS regulation is laudable. It emphasizes the importance of error reporting and the absolute necessity for sound medication reconciliation, infection control, and safe medication practice programs. ■

This guest editorial is reprinted with permission from Wolters Kluwer Health and originally appeared in the December 2007 issue of Hospital Pharmacy.

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 just received a copy of your Oct-Nov 2007 magazine and felt I had to write. I live in Australia and work in a plasma fractionation facility. Because our healthcare system is so different, we are largely unaware of the difficulties faced by patients in the United States. Some of the letters are heartbreaking. Although not a U.S. citizen, I would be grateful if you can continue to send me a copy either physically or in eZine format so the people here who manufacture immune globulins for Australian patients can get an appreciation of how valuable—and valued—their dedicated work really is.

Keep up the splendid work in keeping everyone informed.

—Elizabeth, Australia

Regarding the Oct-Nov 2007 *IG Living* article, "Motivating Cyrus":

For 34 years, I suffered from symptoms of undiagnosed chronic inflammatory demyelinating polyneuropathy (CIDP) and peripheral autonomic neuropathy. By April 2004, I was in a wheelchair, living with unbelievable pain, including bone pain in the feet and skin so painful you could not touch it. My digestive, cardiac and other systems were not working properly, and breathing was becoming very difficult.

IVIG therapy was started and every symptom of 34 years was reduced, or eliminated, by the therapy. I shall forever be grateful to Norman Latov, MD, PhD, of The Neuropathy Association, for initiating the 2003 research article, confirming this use of IVIG. And I will always be mystified by anyone who questions this life-giving use of IVIG.

—Lt. Col. Richardson, U.S. Army Retired, Florida

I have learned that being healthy is a state of mind. Whenever I tell people I have CVID, the most common reply is, "You don't act or look sick." I wake up every morning knowing that my lab work may be a little abnormal, my back may ache from my ITP or I should wear a three-quarter length shirt to cover up my bruise from the IV site. Yet, I still have to live my life and the roles I play—mother, daughter or co-worker. I think you

can only do that if you believe with mind, body and soul that you are as healthy as you make your mind up to be.

—Kelly, Ohio

I am a home health nurse. Please do an investigative article on insurance companies' blatant disregard for their patients when changing their PPO plans in the middle of the year, requiring them to go to a new homecare company and then denying authorization to many patients who desperately need their IVIG. I have a CIDP patient who doesn't exactly fit into the criteria, but who has returned to a normal functioning lifestyle since IVIG. She has been put on hold for three weeks now and is becoming progressively weaker. She soon will no longer be able to work or care for her four children thanks to her insurer. Another patient with hypogammaglobulinemia is being threatened with no authorization for IVIG treatment. If she does not receive her IVIG every three weeks she will become severely ill. She is so scared, she was visibly shaking. This is criminal.

—Home Health Nurse, California

We would like your readers to know about Grifols' reimbursement support services offered to our users of Flebogamma® and Flebogamma DIF® IVIG therapies.

Grifols has experienced reimbursement specialists on staff to respond to product user inquiries and assist patients and their providers in navigating through the various reimbursement issues. If a user has problems obtaining insurance coverage for IVIG therapy, a reimbursement specialist will work to find coverage options that provide a long-term solution. Grifols also has an emergency supply system accessible by physicians who are unable to acquire IVIG for specific patient emergencies. Any patient or provider in need of assistance can contact Grifols customer support at 888-GRIFOLS.

Grifols is committed to working with the IVIG community and providing assistance to help assure patient access to lifesaving therapies.

—Vlasta Prikazsky, Grifols, Virginia

Skin Deep Beauty

By Mark T. Haggard

"Mr. Haggard, is that your daughter?" one of my high school students asked, fixated on the picture of Molly I have over my desk.

"Yep."

"What a beautiful little girl."

It is a good picture: Molly in her cheerleading outfit in the end zone of Boise State University's blue turf. That picture doesn't tell the entire story of her one year of cheerleading, though.

Last fall, when her brothers started playing football, Molly wanted to try the pompoms and the megaphone. As the fall progressed, her cheers of "Lean to the left, lean to the right" turned to "Lean over and get me a tissue," as she faced yet another sinus infection.

"Interception in our direction" became "An Infection in our direction" and "First and ten, do it again!" became "Pre-scrip-tion, Zith-ro-mycin!"

The great quandary of primary immune deficiency disease (PIDD) is that our kids can look so good, yet feel so bad. As a dad, I have no clue that something is coming on, and if I take too long to react, things go from good to bad to worse in a flash.

One of the side effects of Molly's PIDD is that she will inevitably suffer an oral herpes breakout with almost every sickness. If she gets pneumonia, she will have a herpes outbreak. If she gets a sinus infection, she will have a herpes outbreak. If she gets a cold, she breaks out. If her brother looks at her the wrong way, she breaks out. It starts as a blotch of red under her lower lip, then spreads like an August wildfire across her creamy, innocent 6-year-old face.

"Daddy, I don't want to go to school," Molly announced one recent morning, as I was leaving to go to work. "I'm not pretty," she announced, hiding her blemishes behind three Hello Kitty bandages.

The words cut me to my core. I shook my head and answered, "That's not true, Sweetie. Beauty is not on the

outside. It's on the inside. It's what's inside your heart."

"Then my heart isn't pretty," she muttered staring at the floor.

I dropped to one knee in front of my misguided daughter and told her to take off her bandages. "Do your bandages make you pretty?" I asked.

"Um..."

"Sweetie," I continued, "What makes you beautiful isn't something you can see. Tell me, when do you feel pretty?"

"Well," she started, "when I help Mom set the table or when I clean my room."

"When else?"

"When I go upstairs and get my brother's stuffed dog when he's getting his pokey medicine."

"Why does that make you feel pretty?"

"Because it shows my heart is full of love." With that statement she took her bandages from my hand and put them in the garbage.

My wife emailed me at work, later, about the time that Molly was to leave for kindergarten. "Molly decided to go to school," she wrote and attached a picture. While waiting for the school bus to pick her up in front of our house, Molly had climbed the tree and was peeking out from between a couple of branches. Rather than the high-placed ponytail that she was accustomed to wearing, her hair was pulled back into braids exposing her face, scabs and all. Yet just above the coagulated masses, a smile beamed as bright as the daybreak.

An adolescent young lady looked over my shoulder at the picture on the computer screen and said, "Mr. Haggard, you have a beautiful little girl."

Yes, I know I do. ■



A Tale of Two Cousins

By Lauren Gerstmann, MPH

When I recently visited Cincinnati Children's Hospital Medical Center, I met a nurse in the recovery room. Her name is Karla, and she shared a story with me I feel compelled to share with our *IG Living* readers. The story is about her son, Christian, and her sister's son, Corey. Both boys are now 3 years old, both have received immune globulin treatment, and both are survivors. ...

As young adults, Karla and her sister, Debra, led fairly separate lives. Karla spent eight years questioning her way through school, while Debra knew immediately that she wanted to be a nurse. But eventually both sisters became nurses, they gave birth to their first children within three months of each other—and their lives began to converge in ways they never imagined.

After Karla's son, Christian, and Debra's son, Corey, were born,

they spent the first year and a half of their lives together. As they grew, they became inseparable and each sister began to think of each other's child as her own.

Then, at Christian's 18-month checkup, his pediatrician wanted to follow up on a swollen lymph node. "It was a Friday afternoon, and suddenly we had an appointment with the hematology-oncology department for Monday," remembers Karla. Was it leukemia? Lymphoma? A case of an overactive lymph node?

His doctors prescribed Christian an antibiotic to see if he had an unusual infection, and encouraged the family to take a vacation from worry while they waited to see if the antibiotic would help. The family spent two weeks in Florida, and Karla tried not to check on the node. She says now, "I only peeked once!"

After the vacation, Christian's doctors felt his lymph node had decreased slightly, and a node biopsy was negative for cancer. Suddenly, life veered onto a rosier path. They weren't one of those families that receives heartbreaking news from their pediatrician.

But the extended family was again jolted with bad news in February 2007. At a birthday party, Christian was searching for his buddy Corey. He found him napping and woke him. But after a few minutes of horseplay, Corey started screaming with pain. He was irritable and inconsolable. That's when Karla noticed a huge lump on Corey's ear.

Two pediatricians could not figure out what the lump was and, within three days, it had tripled in size. Corey was then seen by Dr. Charles Myers at Cincinnati Children's Hospital Medical Center. Blood tests showed that Corey was anemic. The whole family



Christian and Corey

gathered and waited while Corey had investigative surgery.

Attempting to work despite her worries, Karla was on duty during Corey's surgery. She turned to her co-workers at the hospital for support. "They kept me from falling when we got the biopsy results," Karla says.

The biopsy delivered devastating news: Corey was diagnosed with cancer—neuroblastoma, a very aggressive form. The family was in shock. They had only seen the first signs a week prior. After consulting with Dr. Myers, Debra's husband, Jim, walked out crying and said, "I never imagined that I would have to live my worst nightmare." Until that moment, Karla had known exactly how Debra and Jim felt, because she had been there such a short time ago. But with Corey's diagnosis, their paths diverged.

Doctors put Corey back under anesthesia later the same day and took scans of his entire body, which revealed Corey had tumors in every bone of his body—every finger, every rib. Tumors had invaded his sternum, hip, spine, bone marrow, everything. His adrenal gland was the primary site. The tumor there was at least three times the size of a golf ball. The tumor behind Corey's ear penetrated his skull and was putting significant pressure on his brain.

Within two days of learning he had neuroblastoma, Corey began chemotherapy to destroy the cancer cells, but it also destroyed his functional bone marrow. In March, doctors began harvesting Corey's stem cells so they could be given back to him in a stem cell transplant after chemotherapy was completed. Essentially, Corey's own cells would be used to heal him.

In June, Corey had a tumor in his abdomen removed. It was a tough surgery, and he wound up in the ICU with septic shock after the procedure. The surgery was so difficult that his right kidney suffered some damage. Finally, after his seventh round of chemotherapy, Corey had his stem cell transplant and remained in the hospital for 47 days. He went into renal (kidney) failure because the required follow-up treatment to the procedure, chemotherapy and antibiotic drugs, was so toxic. Corey then underwent dialysis for a couple of weeks, and has since regained much of his kidney function.

*Christian says,
"Corey is sick.
Corey is strong.
Corey is brave."*

Corey's mother said he is a fighter and she believes that Corey's spirit and people's prayers will help him to beat the cancer.

But this family had even more challenges ahead.

Right around the time Corey's stem cells were being harvested, Christian developed petechiae on his chest, belly, arms, and legs—little spots caused by broken blood vessels, which, in turn, can be caused by low platelet counts. When low platelet counts cannot be explained, it is known as idiopathic thrombocytopenic purpura (ITP). Christian's parents immediately took him to the emergency room. Christian had petechiae before, but each time, the cause was benign. This time, Christian's platelet count was very low—13,000—when it should have been 100,000 to 150,000, and this was a danger sign.

While Christian was being worked up in the ER, Corey was a few floors above him in the hematology-oncology ward. But the boys could not visit each other, because each was too vulnerable to infection.

It was a freakish weekend. Cincinnati Children's Hospital Medical Center was so crowded that, after waiting for hours, the family was told there were no doctors available to see Christian and no beds available to admit him. Christian's platelet count had risen slightly to 20,000, hovering just at the border of requiring treatment. The family decided to leave the overcrowded hospital and return the next week for a routine clinic visit.

The next day, Christian spiked a fever and they were back in the ER—only to repeat the same scenario.

But when they returned home and he spiked yet another fever, Karla called the hospital. This time both cheeks and the inside of his mouth were covered with petechiae, and he began vomiting. At that point, everyone knew it was time to stop the back and forth and Christian was immediately admitted to the hospital and treated with intravenous immune globulin (IVIG). Once the IVIG stabilized him, Christian was discharged.

After treatment, Christian seemed to do well. Over the next three and a half months, his platelets drifted back down, but not into the danger zone. However, around Memorial Day, Christian's platelet count plunged ➤

from 192,000 to 5,000. His ITP had relapsed and he was readmitted to the hospital that night. Doctors still weren't sure what triggered the ITP. During this episode, Christian developed hemolytic anemia in addition to the ITP. Now he needed IVIG, a blood transfusion and steroid therapy.

After four days, Christian was once again stable enough for discharge.

Resources

Evans syndrome

Evans Syndrome Research and Support Group
www.evanssyndrome.org

Office of Rare Diseases (catalog of online resources)
<http://rarediseases.info.nih.gov/asp/diseases/diseaseinfo.asp?ID=6389>

Hemolytic anemia

National Heart, Lung and Blood Institute
www.nhlbi.nih.gov/health/dci/Diseases/ha/ha_what.html

MedlinePlus
www.nlm.nih.gov/medlineplus/ency/article/000571.htm

Idiopathic thrombocytopenic purpura (ITP)

Platelet Disorder Support Association
www.pdsa.org

National Heart, Lung and Blood Institute
www.nhlbi.nih.gov/health/dci/Diseases/Itp/ITP_WhatIs.html

Neuroblastoma

The Neuroblastoma Children's Cancer Society
www.neuroblastomacancer.org

MedlinePlus
www.nlm.nih.gov/medlineplus/neuroblastoma.html

For more information on Corey and an opportunity to contribute to his care, please visit
www.milfordcommunityfd.org/Corey/corey_nickell_fund.htm, a site created by the Milford Community Fire Department.

Since that night, Christian has not relapsed. But if he does have another episode of ITP and hemolytic anemia, he will be diagnosed with Evans syndrome, a rare autoimmune disorder in which the body makes antibodies that destroy the red blood cells, platelets and white blood cells. Christian hasn't needed IVIG therapy since May, and he was recently weaned off maintenance steroids, but his parents remain vigilant.

Meanwhile, Corey is home from the hospital, and his future is looking brighter. A biopsy in early August showed that Corey still has cancer cells in his bone marrow, which significantly increases the chances that he will relapse within the next year. But the primary site of his cancer, his adrenal gland, was radiated to eradicate remaining dormant cells, and Corey's post-radiation biopsy was clear of cancer cells. Even so, he is not totally out of the woods.

Advanced neuroblastoma is very difficult to treat, and children with metastasized neuroblastoma treated with stem cell transplant have only a 38 percent chance of survival.¹ Corey's parents are determined to fight the odds. They have signed him up for an antibody therapy clinical trial. The trial is a "search and destroy" mission, testing an antibody to see if it will bind to neuroblastoma cells and either kill them or stop them from spreading. In the meantime, he receives weekly IVIG treatments to shore up his immune system.

Although these two boys have gone so many months without seeing one another, Christian and Corey remain close. They talk on the phone and visit via webcam, and they seem to have an understanding of the situation that goes beyond their years. When asked about his cousin, Christian says, "Corey is sick." Then he'll add, "Corey is strong" and "Corey is brave." ...

I like things to be neat and tidy. I want to be able to explain why these two cousins are going through this, and to write that this will be over soon. But I cannot. Why has Christian's immune system become so vulnerable without explanation? Why has Corey developed such a rare and pervasive cancer? And, why were they affected at the same time, at the same age? I can't find an explanation.

From their mothers, I hear incredible strength and faith. The boys have wonderful medical care and have made great progress so far. Karla tells me, "Prayer truly works miracles." May it be so. ■

¹ Lacayo, NJ and Marina, N: Neuroblastoma at www.emedicine.com/PED/topic1570.htm updated 6/20/2006



Do you have a sore throat? Then you can search the Internet to see if it's strep or a viral infection. Is your knee sore? Then you can search the Internet to see if it's tendonitis or a strained ligament. In fact, most of us probably know someone who has visited one of the major health websites such as WebMD and Yahoo Health, or used a search engine like Google to find information. On a typical August day in 2006, reports the Pew Internet and American Life Project, health searches were as popular as "paying bills online, reading blogs or using the Internet to look up a phone number or address."

Which means it isn't surprising that more than 100 million American adults look for health information on the Internet, according to the study—and that almost two-thirds of them are looking for information about a specific disease or condition.

What may be surprising, though, is that many of those people aren't looking for health information for themselves. At least half of them—sometimes parents, but not always—are looking for information for someone else. "When someone gets sick, it is often the case that friends and loved ones help out by bringing food, taking care of household chores or sending their best wishes," the report explains. "It seems that the Internet provides another way for Americans to show the love: Serving as an online research assistant."

There is one caveat to these findings: Not enough people—as few as one in seven—who use the Internet to look for health information check to see if they are reading quality information, as determined by the source and date of the online posting. Searchers need to find the most current information, posted by or linked to

reputable groups like the National Institutes of Health (NIH), disease foundations or physicians.

In light of this, is it truly helpful for someone who is recently diagnosed with a chronic disease (or his or her caregiver) to use the Internet as a source of key disease state information such as relevant specialists, symptoms, treatment, prognosis, lifestyle and insurance issues?

We tested the effectiveness of searching on the Internet with

three rare—but not exceedingly so—diseases: chronic inflammatory demyelinating polyneuropathy (CIDP), inclusion body myositis and stiff-person syndrome (SPS). We used Google as our search engine, and we consistently used three search terms—the disease itself, the disease plus the words "support group," and the disease plus the word "research." This survey is not a comprehensive study; it's the work of one person spending a day or so wading through Google search pages, with all of the limitations that includes. We simulated a personal Internet search the average patient or caregiver might pursue; there is no science, per se, in our approach.

The results, though encouraging, depended on the disease and how persistent the patient or caregiver might be. Some sites were more thorough than others, like the NIH-related pages (from which many other sites lifted information verbatim). It was difficult to find support group information, although whether this is a fault of the Internet or that the diseases are so little known wasn't clear. One interesting surprise: There was very little insurance-related information, unless it showed up on a discussion board. It's apparently easier to learn about a disease than how to pay for its treatment.

One other result from the Pew study: The Internet helps. "E-caregivers who said the Internet played a crucial or important role were then asked if they got bad information or advice online that made their experience more difficult," the report explains. "Six percent of these respondents said yes; 91 percent of e-caregivers said that was not a problem for them."

Check the next section for a breakdown of what we found. ➤

Chronic Inflammatory Demyelinating Polyneuropathy (CIPD)

Most informative sites

- GBS/CIDP Foundation International: www.gbsfi.com
- National Institute of Neurological Disorders and Stroke (NINDS) Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Information Page: www.ninds.nih.gov/disorders/cidp

The Guillain-Barré Syndrome/CIDP Foundation International (GBS Foundation) and the CIDP entry on the NIH's National Institute of Neurological Disorders and Stroke (NINDS) site are the most informative. Each site has a different approach—the former is more personal, the latter more medical—but both contained the basics for the disease.

Neatest feature

- Neurology Muscular Dystrophy and Neuropathy Institute
Illustration of a damaged myelin sheath on a nerve
www.beverlyhillsneurology.com/cidp
A drawing of a damaged myelin sheath on a nerve, thought to play a role in CIDP. This drawing can be found on the Neurology Muscular Dystrophy and Neuropathy Institute site. There are not many illustrations on these sorts of sites.

Finding support groups

A U.K. site, plus discussion groups, local chapter listings and links to personal websites at several foundation sites, including the Neuropathy Association. There seemed to be more support groups here than for the other two diseases.

- The Neuropathy Association: www.neuropathy.org
- Barbara's CIDP/GBS Site (This is a personal website):
www.geocities.com/HotSprings/Falls/3420

Do the sites work?

The links on some of the personal pages were broken, and the look and feel here wasn't as slick as those sites dealing with stiff-person syndrome. That said, they weren't difficult to navigate.

What about treatment options, specialists and prognosis?

Generally, most sites listed the same treatment and prognosis, and detailed the differences between CIDP and GBS (key in a prognosis). Links to specialists were few, although the Neuropathy Foundation site listed its seven centers in hospitals across the country and the GBS foundation and NINDS sites included links to research studies. The treatment options on almost all sites included both standard prednisone and off-label options such as IVIG and plasma exchange.

Learning about insurance

None

Living with the disease

The discussion forum on the GBS Foundation site, which included topics for expectant mothers, caregivers and teens, seemed to be thorough and well visited.

Inclusion Body Myositis (IBM)

Most informative sites

There were several informative sites to choose from, including The Myositis Association, the Muscular Dystrophy Association and the IBM entry on the NIH's National Institute of Neurological Disorders and Stroke (NINDS) site. These are each medically oriented approaches, though all are written with language that is easy to understand.

- The Myositis Association
IBM description
www.myositis.org/about_myositis/inclusion-body_myositis.cfm
- Muscular Dystrophy Association
FAQs About Inclusion Body Myositis
www.mdausa.org/research/ibmfaq.html
- National Institute of Neurological Disorders and Stroke (NINDS)
Inclusion Body Myositis Information Page
www.ninds.nih.gov/disorders/inclusion_body_myositis

Neatest feature

We came across a site that cataloged six years' worth of summaries on IBM research, posted on a website by a Canadian layman who suffers from the disease. This is an impressive feat, if only for the diligence of updating a website for so long.

- Inclusion Body Myositis (IBM): Site presented by Bill Tillier
members.shaw.ca/btillieribm

Finding support groups

IBM seems to have a variety of support groups, whether foundation-related or a local site.

- The Myositis Support Group Website: www.myositissupportgroup.org

Do the sites work?

We found very few broken links and a professional feel to all but several of the personal sites. And even some of those were impressive.

What about treatment options, specialists and prognosis?

There is very little positive news for IBM patients, and each of the sites addressed that in one way or the other. Interestingly, there were apparently more doctor-related sites here. Typically, most sites listed the symptoms, the limited treatment options (no cure and no standard course of treatment) and the inevitable prognosis.

Learning about insurance

The Myositis Association site, in discussing treatments, notes that treatment with Alemtuzumab is expensive and not covered by insurance. Otherwise, as with the other diseases, there is very little information.

Living with the disease

The Canadian layman's site tells his story and recounts his particular troubles with physicians who were, for whatever reasons, reluctant to diagnose his illness as IBM. He also discusses his decision not to take any medication.

- My Personal Story: Bill's Diagnostic Story So Far
members.shaw.ca/copingwithillness/MyPersonalStory.htm

Stiff-Person Syndrome (SPS)

Most informative sites

The SPS entry on the NIH's National Institute of Neurological Disorders and Stroke site was very informative. Also, the National Organization for Rare Disorders, though not quite as complete as NINDS, was informative. Both contained laymen-style language that described the disease, plus a variety of links to disease foundations, research and the like.

- National Institute of Neurological Disorders and Stroke (NINDS) Stiff-Person Syndrome Information Page
www.ninds.nih.gov/disorders/stiffperson/stiffperson.htm
- National Organization for Rare Diseases
www.rarediseases.org

Neatest feature

The research link on the NINDS site. This allows patients and caregivers to check to see if studies are looking for subjects.

- National Institute of Neurological Disorders and Stroke Funding and Research
www.ninds.nih.gov/funding

Finding support groups

None came up in the United States, although there were several in the United Kingdom, including Contact a Family, which works with families and children.

- Contact a Family
www.cafamily.org.uk/Direct/s55

Do the sites work?

Most of the websites that we found were easy to navigate and the links appeared to be current and active. WebMD was a little clunky (looked like it had been built from a template), with lengthy author's information listed first and the disease description written in more

complicated language than its counterpart on the Mayo Clinic site, for example.

- Mayo Clinic
Stiff person syndrome: Can it be treated?
www.mayoclinic.com/health/stiff-person-syndrome/AN01377

What about treatment options, specialists and prognosis?

Few sites, save those operated by clinics and physicians' offices, linked to specific specialists. The treatment options on almost all sites included both standard practice muscle relaxants and pain medications, as well as off-label options, such as IVIG. The prognosis information was all about the same. WebMD also had a lengthy discussion of the medical and legal pitfalls (found by clicking on the follow-up link on the right side of the page).

Learning about insurance

None

Living with the disease

We found a truly amazing site called Stiffman.org. This site is posted by a woman who has had the disease for 13 years. It includes links to a support group and her personal experiences (including a journal). The site has an especially intriguing section simply called "Coping," which has links and advice for those with a chronic illness.

- Stiffman.org
Personal website
www.stiffman.org

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Strengthening Ashley

A Young Family Finds Hope in IG Therapy

By Jim Trageser

Like any young couple, Jenn Sullivan and her husband were thrilled to welcome a new child into their family. Jenn had just turned 19, her husband was still shy of 21, and when baby Ashley was born in April 2000, she was perfect. Life couldn't have been any better for the young family living in upstate New York.

But as Jenn explained in a series of emails, Ashley's health took a serious turn for the worse between the ages of 20 months and 2 years.

"Up until that point, there had been some odd things we had noticed, but nothing seemed to fit any set pattern, per se.

"For example, she had 'rattly' lungs, tachycardia, purplish feet, a continual clear runny nose, terrible GERD (gastroesophageal reflux disease), a diaper rash so severe it was treated with burn therapies like SSD ointment and whirlpool therapy at the hospital. In fact, her vaginal area was completely devoid of the epithelial layer of skin—her urine or some virus had burned it off, so she would bleed and scream horribly upon soiling a diaper. It was so awful! We wept with her.

"She vomited constantly for no apparent reason, [and] she was quite late in hitting her growth milestones—walking, crawling, sitting, etc. As odd as all of this was, her doctors appeared unalarmed."

More confusing for the family was that Ashley seemed perfectly healthy when she was born—and Jenn's pregnancy had been perfectly normal.

Still, as Jenn wrote, things got even tougher for Ashley when she was 20 months.

"She was diagnosed with psoriasis—she had awful cradle cap that just never went away—and hypothyroidism, and she was put on 50 mcg of Synthroid. There were literally hundreds of tests and scans done in this timeframe



but nothing more could be determined. But there was something wrong! She would go days without eating, she would sleep 16 to 18 hours straight and she developed a very 'barky' cough. She did have a few ear infections, but nothing abnormal, and most kids do get them. She was getting her vaccinations on time, as scheduled.

"The doctors were perplexed! Something was wrong—but what?"

In December 2002, Ashley was admitted to the hospital with double pneumonia.

"We were so terrified," Jenn wrote. "She did eventually recover, but not for long. All of 2003 she fought one lung infection after another. She was completely off of the ➤

charts at this point for her height and weight, as she had stopped growing long ago. She ended up hospitalized again after what we thought was an asthma attack in November 2003—at age 2 1/2. She was sent home later that weekend and we were told she had another pneumonia—we were so sick of hearing that by now!”

Like many families facing an unknown diagnosis, the Sullivans wanted answers as to what was wrong with their little girl.

“This poor baby needed help and it seemed no one could give it to her. That week we were back at the hospital and we refused to leave! I will forever remember one of the residents there, who had remembered us from our previous admission, taking my hand and saying, ‘Something is wrong with your daughter and I promise you, we will find out what it is this time.’”

Before they did, though, Ashley had to fight for her life.

“That next morning, we almost lost her—her blood pressure was up to 180 (sleeping!) and her pulse was down to 90 on full oxygen. The doctor in the room was ready to intubate but, fortunately, Goddess bless, it did not come to that.

“Still, we knew our little girl did not have much time. The doctors had to act—fast! Again, while she was pumped full of fluids, steroids, antibiotics, etc., she had hundreds of tests, scans, samples and even a bronchoscopy-thoracoscopy done to her small little body.”

“When children do ask questions she tells them, ‘I am a SCID kid’ and walks away. She makes no apologies for being the wonderful, free spirit that she is, in her own way.”

After a month of hospitalization, doctors finally ran a test that showed Ashley had no immune system. But even that didn’t tell them why she was sick.

“Finally, we met with the chief of immunology, a wonderful doctor who said that, on a whim, he wanted to test for SCID (severe combined immune deficiency). He said he was almost certain she did not have it, as

most undiagnosed children pass away by the age of 2 and at this time she was 3 1/2! Well, sure enough, that was it! She had SCID, according to a doctor at New York University.”

SCID is caused by a genetic abnormality, and so doctors then ran a genetics background on Jenn and her husband to try to pinpoint Ashley’s condition.

“As it turns out, Ashley has one of the most rare mutations of SCID—ADA, virtually unheard of,” Jenn wrote.

The adenosine deaminase (ADA) subtype of SCID, specifically, is caused by lack of the adenosine deaminase enzyme, which leads to a compromised lymphatic system. SCID affects about one in 100,000 babies, and ADA, only a tiny sliver of those.

Still, as any family who has been down this road knows, any answer is better than uncertainty.

“As frightening as it was, at least we had a name and some treatment options. Since SCID-ADA kids do not generally do well under chemo for bone marrow transplants, Ashley was put on IVIG and an IM injection known as PEG-ADA, or Adagen, two times a week. Under this, she began to improve.”

Not that Ashley’s day-to-day life can be considered normal. Three years ago, doctors found she has pulmonary fibrosis. She also has adrenal insufficiency and hypoglycemia, and she had a mediport put in. In 2005, she was diagnosed with autoimmune hemolytic anemia and delta agranulocytosis (a blood clot disorder). In the summer of 2006, doctors took a bone marrow sample, and it came back fine, giving the family some good news. But in September 2007, she developed keratitis in her right eye, causing serious degradation of her vision.

Still, Jenn says the family refuses to allow Ashley to be defined by her medical challenges. As Jenn put it in an email, “She has SCID-ADA; SCID-ADA does not have her!”

As much as possible, the family is mainstreaming Ashley.

“She attends a regular public school with the assistance of a personal aide, a vision therapist, an occupational therapist, a speech and language therapist and a modified phys-ed program. She loves to play Barbie and school and with her baby dolls. She loves visits to her family members’ homes, she loves dogs, she loves to color, she loves Nickelodeon. She is every other kid, just a little extra special.”

Jenn wrote that she and her family know they’re lucky Ashley was born today, when there are options for treating SCID.

“SCID-ADA and people with SCID-ADA variants (like Ashley has) are less likely to receive the bone marrow transplants that have helped ‘cure’ so many patients, as

their bodies do not handle the required post transplant chemotherapy as well as other primary immune deficiency patients. Therefore, they, like Ashley, must rely on IVIG and medications like PEG-ADA (Adagen)."

In the past, a diagnosis of SCID was a death sentence. Today, though, with treatments such as immune globulin, patients are living longer than ever. And Jenn wrote that Ashley's approach to her challenges is positive and upbeat.

"Because of all she has been through, Ashley is a very empathetic, thoughtful child. She is happy and talkative and very easy and lovable to be near.

Parents need to be
willing to lean on others,
no matter how difficult
it can be to swallow
your pride and admit
you need help. "There
is no 'Martyr Medal.'
Accept help!"

"Since she did have so many random illnesses prior to her official diagnosis, she never got to experience playgroups, playdates, daycare or any of the other activities young children enjoy in their baby-toddler years. She was constantly with doctors, nurses, extended family (all adults), and that kind of shaped her into a 'mini-adult' with a pretty extensive vocabulary.

"She is very good about communicating how she feels, whether it is a physical pain, fear, happiness, nervousness, etc. She is an old pro (unfortunately) when it comes to accessing her mediport and starting IV lines, so she doesn't get too nervous about that—mostly just new doctors or clinics that she is unfamiliar with. And even that tension eases away quickly! The Women and Children's Hospital of Buffalo is great!

"As far as being in more kid settings now, like school, she has just learned to accept her limits. She knows she has to wear her glasses and medic ID tag, she cannot play in any way that could affect her bleeding disorder (playgrounds, etc.), she needs to eat well so her blood sugar doesn't drop, she has to use sanitizers religiously, etc.

"To her, it's just life and she copes with it wonderfully.

When children do ask questions she tells them, 'I am a SCID kid' and walks away. She makes no apologies for being the wonderful, free spirit that she is, in her own way."

For other families facing a diagnosis of SCID—or any life-altering condition—Jenn wrote that parents need to be willing to lean on others, no matter how difficult it can be to swallow your pride and admit you need help.

"There is no 'Martyr Medal.' Accept help! This is an overwhelming, frightening time, and you need people to rally around you. Do not be afraid to ask for, or accept, any and all forms of help offered.

"For help with monetary concerns, such as meal vouchers, parking passes and toiletries for you, ask your RN or a social worker—they are usually great resources! When people do come to visit, do not feel as though you have to keep up appearances. Cry if you need to, vent, laugh, whatever you feel! There is no right or wrong emotion. Each person is different.

"With this in mind, be sure to keep your fears, feelings and emotions separate from your ill child. Focus on activities to do together, like card games, play dough, watching movies, etc.

"Inevitably, the tough questions do arise: What's wrong with me? Why am I sick? I always told Ashley that we don't always know the answers, but, if we enjoy each day and do our best to get through the rough times, the Goddess would see us through. Be honest with your child, but optimistic!"

In addition to tending to your family's—and your own—emotional and spiritual strength, Jenn also advised that staying organized is a huge help.

"Keep a notebook of all medications your child is given, which doctors are involved in their care, and brief notes from each consult and procedure. This makes communication easier and more effective.

"Keep an overnight bag handy—a change of clothes for you, games, books, puzzles, small toys for your child—in case of emergency trips to the hospital. ... Invest in a small, portable DVD player for ER admissions."

And for families facing a primary immune deficiency, Jenn advised staying informed, but letting the medical professionals be the experts.

"Do not over-research—each variant of primary immune deficiency is different. Ask your doctor or RN for reliable books, publications and websites. There is a great web support group through Duke University for patients and families (www.scid.net/facilities.htm)."

Her final bit of advice, though, may be the most critical: "Most important, never be afraid to ask, ask, ask questions." ■

About Long-Term



At first glance, nothing seems extraordinary about the 11-page report. It has lots of tiny type, lots of acronyms (ADR [adverse drug reaction] and CRF [case record form] among them), and lots of sentences that require a couple of reads to understand.

But it is interesting. The report details a 10-year study of the long-term safety profile of an intravenous immune globulin product, Octagam, in the treatment of various primary immune deficiency diseases (PID), secondary immune deficiency diseases (SID)

and autoimmune diseases. The study was funded by Octagam manufacturer Octapharma, and there is good news: This drug produces few side effects, and those it does produce are almost always minor and confined to certain groups of patients. Among the most significant numbers? Only 0.35 percent of the approximately 93,000 infusions received during the study resulted in some type of adverse event. And some 95 percent of those adverse reactions weren't serious.

The study, published in June in the journal *Pharmacoepidemiology and Drug Safety*, is one of the most thorough and complete surveys of the effect of this kind of drug ever done, according to Melvin Berger, MD, the director of the Jeffrey Modell Center for Primary Immune Deficiencies at the University Hospitals of Cleveland.

"Ordinarily," he says, "when we do something like this, we get limited information. The average licensing trial gets 40 to 50 patients at six to 12 sites. With this study, you have more than 6,300 patients at 310 sites. We've never been able to gather the depth of data like this before."

The results do not mean that all IVIG drugs will perform the same way, say the study's authors. And Dr. Berger cautions that not all of the results should be accepted immediately,

especially those that suggest that IVIG dose and infusion speed don't cause adverse reactions. But researchers on the study suggest the results do generally bode well for IVIG patients.

"In [the] case of marketing a new product, a pharmaceutical company, as well as the users, will always expect a very good tolerability of the new drug. However, the ratio of side effects [in this study] fell below the ratio that had been known for any other IVIG at the time when marketing of Octagam was started in 1995.

Study Basics

Octapharma researchers, Anette Debes, PhD, Maria Bauer, PhD, and Sybille Kremer, MD, tracked data from 310 sites in Germany from 1995 to 2005, compiling information from 6,357 people receiving Octagam including patient characteristics, treatment parameters and how often each suffered an adverse reaction. All told, the patients received 92,958 infusions of Octagam, a significantly higher number when compared to a typical U.S. drug trial, where data is collected from only 500 to 750 infusions.

In addition, each infusion was documented in detailed case record forms, which Dr. Berger cites as one of the study's strengths. Every patient's physician was paid to submit the case record forms, which are more complete than the patient reports a doctor would usually fill out. This comprehensive data allowed researchers to get a better handle on adverse reactions. In routine treatment scenarios, ADRs are often noted only when a patient complains, and not necessarily in any systematic way. Using the case record forms, the researchers were able to track every side effect, large and small.

The three doctors were excited by the study results and readily agreed to answer questions submitted via email. They combined their responses to help alleviate any problems that might be caused by language differences and distance.

"For patients, physicians and payors, it is important to have drugs with a frequency of side effects that is as low as possible," they wrote. "At the time of product licensure, there is only limited information available on tolerability, since data resulting from clinical trials comes from small numbers of well-selected patients fulfilling certain eligibility

IVIG Therapy

By Jeff Siegel

criteria who frequently do not resemble those patients that will be treated in daily clinical practice.”

The most important result is the very low frequency of side effects seen daily and the low frequency of side effects seen in patients regardless of their indication, disease, total dose or rate of infusion. The doctors wrote, “These results have encouraged Octapharma to pursue approval for additional indications for the product and to investigate increasing the maximum infusion rate and concentration of IgG in the infusion solution.”

All told, side effects were noticed in only about one-third of 1 percent of the total number of infusions given. Among the side effects, rigors (chills) were reported most frequently, followed by fever, headache, nausea and flush. Ninety-five percent of side effects were mild or moderate. In addition, the doctors explained, the study showed that not only is the risk of a side effect significantly less than one infusion out of 100, but there are no clear predictors for the occurrence of a side effect. That means that a patient who experienced a side effect with one infusion of Octagam is not necessarily predisposed to further side effects and, therefore, will probably tolerate another infusion.

“I think the numbers for side effects are kind of what we expected,” says Dr. Berger. “But overall, the study shows that this particular drug and gamma globulin in general are well tolerated.”

More Findings

The results showed several other intriguing trends:

- Disease seemed to determine side effect. Patients with PIDD or SIDD were more likely to experience fevers, while patients with autoimmune neurological conditions or ITP (idiopathic thrombocytopenic purpura) tended to have more headaches. “I’m not sure we were surprised to find this,” says Octapharma’s Judi Miller, vice president of medical affairs, “but I think it is, however, of interest to patients and physicians as it gives them a clearer idea of the types of ADRs they should expect or tell their patients about.”
- Disease seemed to determine side effect frequency, also. Adverse reactions occurred in about one of 100 PIDD infusions, compared to one of 200 SIDD infusions. Says Miller: “The huge numbers of patients and the

diversity of diagnoses included also enabled us to get a better understanding of the tolerability of patient subgroups—in other words, which patients experience which side effects.”

- No patient with SCID (severe combined immune deficiency) experienced an adverse reaction. This is noteworthy because SCID patients—who don’t have T cells and B cells—can’t produce antibodies and would be expected to suffer allergic reactions to a totally foreign protein like IVIG.
- Patient age, which seemed to be a factor in previous studies, didn’t matter as much here. Children, who are normally expected to be most vulnerable, appeared to have very few adverse reactions.
- The low level adverse reactions in CIDP (chronic inflammatory demyelinating polyneuropathy) patients were as much as 100 times less than those documented in other studies.
- Headaches also didn’t occur as frequently as in other studies, again as much as 100 times less.

Still, Dr. Berger says there are some areas where physicians and patients must remain cautious. “We have to be careful about how we read the results,” he says, pointing to the findings that don’t associate infusion dose and infusion speed with adverse reactions. This is one of the few studies to find this, and it goes against much of the data recorded in clinical trials in the United States. He thinks more research needs to be done before any conclusion can be reached.

Nevertheless, the study has broken much ground, say many immune deficiency experts who have seen it. The information can be put to good use as research continues.

“This prospective observational study is important as it provides data on the tolerability of an individual brand of IVIG in routine clinical practice, in a wide spectrum of patients and applications,” the three Octapharma doctors wrote. “This publication—the first to provide 10 years of tolerability data—will hopefully provide both healthcare professionals and patients with data to address many of their previously unanswered questions and concerns.”

Moreover, it provides much needed information that can be used for the evaluation of tolerability of all IVIG solutions. And that’s news that is welcome for IVIG patients and their families. ■

The Patience of Patients

By Ever Fecske

Patients like us must have the most patience. In fact, we are the most patient of patients—and that is an understatement!

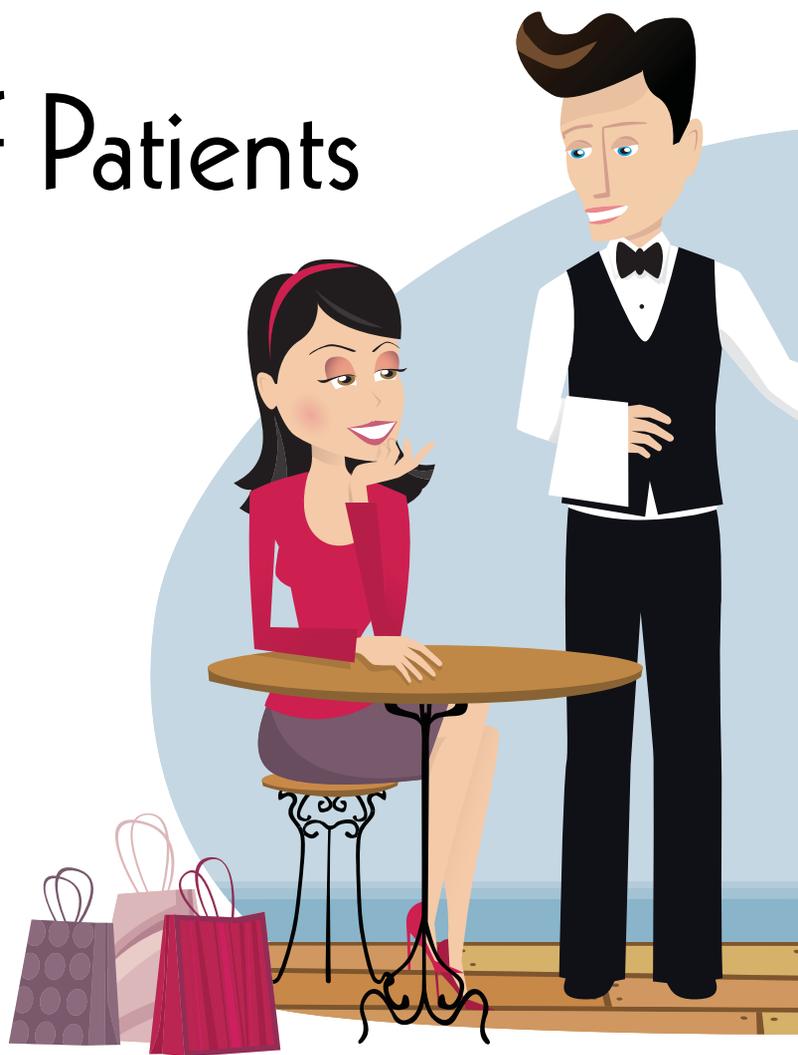
What I mean is that those of us who are chronically ill have to put our internal clock aside when it comes to getting well or even feeling a little better. We all have moments when we can't remember the last time we felt perfectly well physically, and unfortunately there is no countdown or calendar to mark off the time we must spend until we regain our health. It sure would be nice if I could get an exact date I could look forward to: Ever, on January 15, 2010, you will be cured. Then I could be patient.

Most of us don't have a clue as to when the time for a cure will come or if we will ever be completely cured. There are days, weeks and months that feel endless, when it seems as though one procedure morphs into another. You can only keep going, hoping you are heading in the right direction, heading toward a solution. So, we have to be patient without knowing how long we must wait.

Yep, patience is tough. Think of how patient we have to be: Can you think of many people who can regularly sit still for four-plus hours with a needle in their arms? When I really look at it, I find that patience is probably one of my strongest virtues—one that is exercised too often. I have met some chronically ill children who are amazing, and they have shown even more patience than I can ever say I have. Yet I think I am actually pretty patient. I am willing to wait as long as it takes and do whatever it takes to reach that day I am waiting for. Only I wish I knew when it was coming.

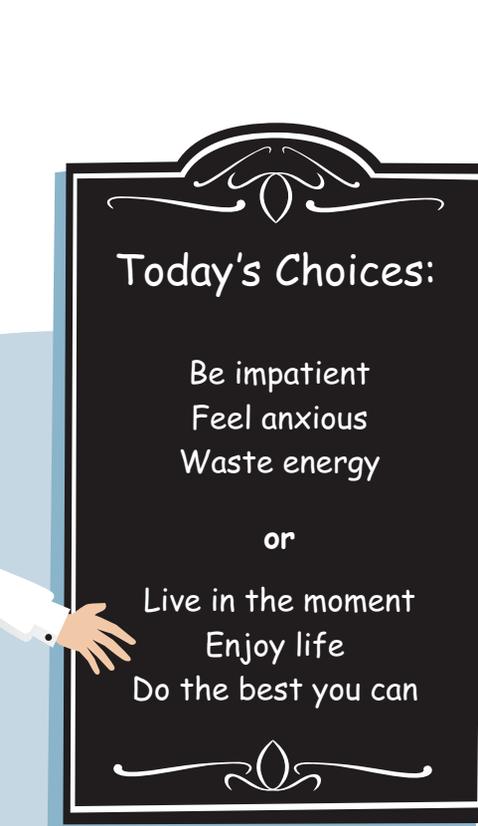
So what do I do to overcome the ants in my pants when it comes to waiting for a cure?

I enjoy life to whatever degree I can. I make an effort to occupy myself and take my mind off how I feel or what procedure is coming next. Like the cliché, I have learned to enjoy the moment and not to care about the next one until I get there.



Recently I went to Disneyland. That place will do it every time. My mind was completely occupied with the fun I was having and the joy I found in watching all the little girls dressed up as their favorite princesses.

But, I can't go to Disneyland every day, so I have found other things that I can do that also bring me joy. I go to Target all the time. I know it's funny, but there is so much to do there, something for everyone. On the home front, my family and I watch baseball together and cheer really loudly. Or we have "Law and Order" marathons. After a few hours of the crime show, we all feel like detectives. These are easy activities that completely occupy me. I have also started my own business. It's more of a hobby, but I love it, and I have placed some of my product in small stores. Now I am patiently waiting to see if they sell.

A hand in a white sleeve points to a black sign with white text. The sign is framed with a decorative border and contains two sets of choices separated by the word 'or'.

Today's Choices:

Be impatient
Feel anxious
Waste energy

or

Live in the moment
Enjoy life
Do the best you can

Ha! There are other things to be impatient about besides your health.

I admit there are times when I lose patience because I simply don't want to wait anymore. I long for the certainty of things coming to a conclusion. I find peace in knowing

that after February comes March, and I have no doubt that year after year I can count on that.

In contrast, when the uncertain state of my health shows no sign of an end, I succumb to impatience. We can all relate to these feelings, but we have to find a way to overcome the anxiety, tension, frustration and uncertainty. The gratification of answers and solutions to our health problems always seems out

of reach. I suppose this is the test and the lesson. We won't always have the answers; even our doctors don't have the answers. Maybe instead of looking for answers all the time, we should enjoy that time we're wasting on impatience.

The irony of impatience is that it can trigger feelings—dissatisfaction, distress, anger—that can hinder our ability to heal. We waste energy worrying about how things are not changing and fail to appreciate the aspects of our lives that are great. We may not be able to do anything today, at this moment, to directly change the state of our illness, but by simply not worrying about it and, instead, living in the now, we will help ourselves tremendously.

When I am feeling frustrated, about to lose my patience, I remind myself of the progress I have made in some areas of my life. I'm proud that I went back to school. It is so

hard, but I am doing it. I'm sure there are many things in your lives you can also be proud of, too. We need to remind ourselves of our great and small accomplishments and be proud of what we have done every day—even on the days when managing to get out of bed and showered is our greatest accomplishment. Keep in mind that on other days, you will be able to do more.

Of course we'll have setbacks. There are some things we used to do that our conditions prevent us from doing anymore.

For me, I always thought I was going to be a singer, name in lights, NYC, private dressing room, the whole bit. But since I was diagnosed with a lung disease that directly affects my ability to sing, I had to rework my goals. It may be that one day my lungs will heal and my singing career will take off, but until then, I have set my sights on something else. At first, when your plans have to completely change, it's devastating, but in time it gets better and something else will become just as exciting and you will feel just as motivated to achieve success.

It's losing patience with ourselves that can cause the most damage. We all have expectations for ourselves, where we see our lives going and what we are going to accomplish. I don't think we should lower those expectations but maybe it is important to make some adjustments. For example, now I keep all my goals short-term. One of my goals is to earn a B in all of my classes. I believe I can achieve this goal even if I need to take a sick day here and there. When I accomplish this goal, I will feel good about myself and feel confident when setting more goals.

When it comes right down to it, I say, "Love yourself!" Accept and understand that sometimes we are weak, fragile and imperfect, and that's OK. Only with this understanding can we forgive ourselves our weaknesses.

We are capable of doing the best we can. If I wake up one morning knowing I have a list of things to accomplish and I only get to half of the list because I'm tired and need to rest, it's OK. In that moment, I did the best I could, and the patience I allow myself will also allow me to be my best friend and cheerleader. Life is exciting, rewarding and worth every minute of patience.

I can't wait! ■



IG Reimbursement: How Did We Get Where We Are Today?

By Michelle Vogel, MPA, and Kit-Bacon Gressitt

Immune globulin reimbursement is a critical and complex problem, affecting the lives of thousands of people living with chronic diseases. On Jan. 1, Medicare reimbursement for hospital outpatient IVIG therapy was reduced, a potentially life-threatening change—and a confusing one, given the recent history of IVIG reimbursement. ...

IVIG

Immune globulin products (intravenous, IVIG; subcutaneous, SCIG; and intramuscular, IMIG) are manufactured from plasma, a component of human blood, pooled from thousands of donors. IG products are expensive to manufacture and distribute, yet life-long IVIG therapy is critical to the health and well-being of patients with a wide variety of chronic and often rare diseases.

This sets the stage for expensive treatment for conditions with which few practitioners, decision makers or insurers are familiar—which, in turn, sets the stage for challenges to fair, reliable reimbursement for a lifesaving treatment.

A Convoluted History

But this is not such a new problem. It didn't begin with passage of the IVIG reimbursement method mandated by the Medicare Modernization Act of 2003 (MMA). In fact, reimbursement for IVIG has been a longer-term problem for the immune globulin community, because of the historical debate about how to define immune globulin: blood product, biologic, or single or multiple source drug. Each of the three categories bears with it a different method for calculating its Medicare reimbursement rate.

In 2002, the Balanced Budget Refinement Act (BBRA) resulted in implementation of a new method for reimbursement for drugs, including IVIG, in the hospital outpatient setting. The new methodology miscategorized IVIG as a multisource drug, which is equivalent to a generic drug category. The IVIG community attempted to explain to the Centers for Medicare and Medicaid Services (CMS) that there are no generic IVIGs and, therefore, IVIG could not be classified as a multisource drug.

Eventually, CMS changed the IVIG status to single source drug, and its reimbursement was based on a percentage of average wholesale price. Although this reimbursement method did typically cover the cost of both the product and its administration, IVIG is literally a blood product, and changing market and supply conditions of blood products could reverse the effectiveness of this type of reimbursement.

With the understanding that inadequate reimbursement for blood, blood products, and plasma-based and recombinant therapies could present a barrier to patient access, the BBRA called for the secretary of the U.S. Department of Health and Human Services (HHS) to create a separate payment category for these products.

So, in September 2002, the Advisory Committee on Blood Safety and Availability (ACBSA), of HHS, directed the CMS to create a reimbursement system for blood products based on current-year acquisition cost plus the actual total cost of administering such products and related services, rather than on the cost of the previous year's hospital outpatient claims. According to ACBSA, this acquisition and administration cost formula is critical to ensuring fair reimbursement of blood products, including IVIG, because their cost is affected by the varying supply of donated blood and plasma in the United States. A market-based formula assures that reimbursement reflects market price changes.

In the meantime, the ACBSA, the Food and Drug Administration (FDA), the House Appropriations Subcommittee on Labor and HHS consistently defined IVIG as a blood product and recommended that CMS recognize it as such. And, in May and August of 2003, the Protein Plasma Therapeutics Association and the Immune Deficiency Foundation (IDF) requested that the ACBSA recommend CMS once again recognize IVIG as a blood product. The ACBSA members agreed and made the recommendation to CMS.

However, when CMS released its blood product reimbursement formula in the 2003 Medicare hospital outpatient prospective payment system, the agency excluded IVIG from its list of blood products.

Formidable Obstacles

The IVIG community challenged the CMS classification. The hurdle to achieving a solution at first seemed small, but it ultimately proved formidable: When Congress passed the MMA in 2003, the 415-page bill contained a small provision that adopted the CMS classification, excluding IVIG from the list of therapies identified as blood products. Instead, Congress included IVIG under the regular drug reimbursement formula, despite the House Appropriations Committee's 2003 recommendation otherwise.

Classification as a regular drug drastically reduced IVIG's reimbursement rate, lowering reimbursement in all sites of care (hospital, physician practice and home). The reduced reimbursement has prevented many healthcare providers from purchasing IVIG, because the total cost of acquisition and administration exceeds the Medicare reimbursement rate.

Consequently, when the MMA reimbursement formula for IVIG was implemented in 2005, many Medicare patients were transferred from their physician's office or infusion suite to the hospital outpatient setting, often causing poor health outcomes for patients whose diseases cause them to be at high risk of acquiring infections in hospital settings.

According to an HHS report by the Assistant Secretary of Planning and Evaluation (ASPE), by 2006, 42 percent of Medicare beneficiaries were shifted from the physician's office to the hospital outpatient setting to receive IVIG. A report by the HHS Office of the Inspector General (OIG) also reported that 61 percent of responding physicians indicated they had sent patients to hospitals for IVIG treatment, largely because of their inability to purchase IVIG at or below the Medicare reimbursement amounts. Despite the reports' findings, no policy recommendations were made by either agency.

The hospital outpatient reimbursement rate was then reduced in January 2006, and many hospitals could no longer afford to continue treating with IVIG. A survey conducted by the IDF of hospital pharmacy directors found that 32 percent of hospitals reported turning away patients for IVIG treatment at some point during 2006.

Through each of the reimbursement reductions mandated by the MMA, members of the IVIG community have offered many solutions to help restore access to IVIG, including declaration of a public health emergency to allow CMS to adjust the reimbursement rate, reclassification of IVIG as a blood product, asking the secretary of HHS to determine an add-on payment to the average sales price (ASP) formula, classifying IVIG as a biologic response modifier under the chemotherapy administration code, etc.

Current Situation

Still no solution has been achieved, and now CMS has reduced reimbursement for all drugs offered in the hospital outpatient setting, including IVIG, from ASP + 6 percent to ASP + 5 percent. CMS has also reduced the IVIG hospital outpatient pre-administration fee by 50 percent. Both of these changes are effective Jan. 1. This is a devastating blow to IVIG patients who have been shifted to hospitals as the site of care of last resort. CMS is also scheduled to eliminate coverage for treatment of certain infections that are acquired while patients are hospitalized, effective October 2008. This is yet another blow to immune-compromised patients, many of whom have no other site-of-care options.

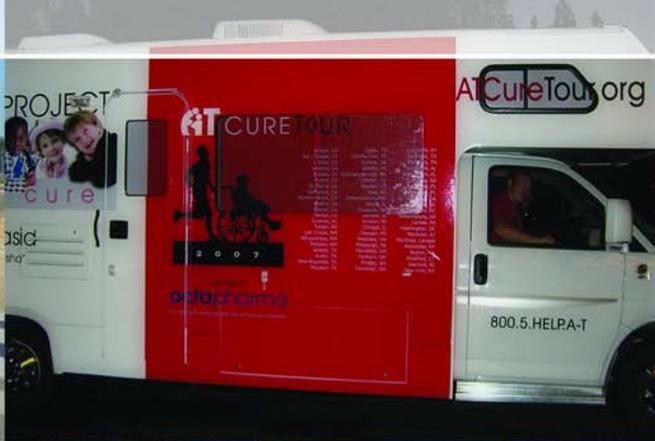
Knowing late in 2007 that these reimbursement reductions were coming, and in response to three years of failed attempts to resolve the IVIG reimbursement and access crisis, the Alliance for Plasma Therapies organized a critical meeting of the minds, held on Sept. 18, 2007. Alliance representatives of patient and physician organizations, professional societies, manufacturers, distributors and specialty pharmacies met with Deputy Secretary of HHS Tevi Troy, CMS Administrator Kerry Weems, Deputy Administrator of CMS Herb Kuhn and HHS Senior Advisor for Blood Policy and Executive Secretary for the Advisory Committee on Blood Safety and Availability Jerry Holmberg.

Participants in the meeting, including the CMS representatives, agreed the meeting was the first step toward creating and maintaining a productive working group, including members of Congress and the IG community, with the goal of finding the best solution to restoring access to IVIG for all patients who rely on this therapy in all sites of care.

However, until this emerging collaboration achieves a solution, patients will continue to experience difficulty accessing their IVIG therapy—and the Jan. 1 reduction in hospital outpatient reimbursement is exacerbating the crisis.

We encourage you to share any immune globulin access problems you experience. We want to help! Contact *IG Living*, your elected representatives, your national disease state organization and the Alliance for Plasma Therapies at www.plasmaalliance.org. ■

Note: For updates on changes to reimbursement or if you need assistance in finding a site of care for your IG treatment, please contact us at editor@igliving.com.



63 for a Cure



By Jeff Siegel

When Tim Borland, with his wife and two children, pulled into the parking lot at the elementary school in suburban Montreal, they weren't sure what they would find.

"I had never been to Canada," says Tim, who grew up in Southern California. "When we crossed the border, I didn't have any idea what to expect. But when we got there, it blew the roof off my expectations."

And why not? Hundreds of children were waiting for the Borlands, eager to welcome them to their city and their school. They knew why Tim was there, and they wanted to let him know how much they appreciated it. Tim was there, on the day before Halloween, to run 26.2 miles to raise money for one of their classmates who is suffering from ataxia telangiectasia (A-T). A-T is almost always fatal, and patients usually die in their teens or early 20s.

This stop in Montreal was the 58th consecutive day that Tim had run 26.2 miles, the distance of a marathon. He would run five more marathon distances over the next five days. All told, he ran 26.2 miles—sometimes in organized events, sometimes not—63 times in 63 days. Tim didn't do it to set a record or garner fame for himself; rather, he did it to bring attention to A-T, a disease that is as mysterious as it is deadly.

"That was always my mental focus," says Tim, who admits there were times over the two months when the thought crossed his mind that he could be doing something else other than yet another 26.2-mile run. "It goes back to my mission and my purpose. There is so much that needs to be done for A-T that your heart goes out to all those kids. And if I focused on that, then I was that much more on target."

63 in 63

So how crazy does someone have to be to run 63 marathons in 63 days? Not much, but it does help, says Michelle Borland, who has been married to Tim for five years. They have two children, Kailey, 3, and Colton, 17 months, and they're expecting a third child in the spring.

"My first reaction, when Tim told me, was that he was crazy," Michelle says with a laugh. "But that's because I had no idea of the kind of reaction we would get from

the families when we did it. I had no idea how much they would get behind us."

Tim came to the project three years ago after meeting a 16-year-old girl named Cathryn Achilles, who suffered from A-T. Through her family, he met other families with children with the disease. Tim ran in several events to raise money for the cause. "My interest just continued to grow and flourish. And I started to get this idea about the marathons about a year ago, and it just kind of took off from there," he says.

The marathon-sized marathon across the country, called the A-T Cure Tour, began in Anaheim, Calif., when Tim ran the Disney Half-Marathon twice. The A-T Cure Tour took in 12,000 miles of travel through more than two dozen states, the District of Columbia and Canada. Tim finished at the New York City Marathon, one of five sanctioned events on the schedule. The rest of the time, Tim ran 26.2 miles on streets, parking lots and trails—wherever he could put together the distance. The A-T Children's Project, based in Deerfield Beach, Fla., arranged the schedule, working with A-T families in each city who wanted Tim to run there. His schedule was much the same every day: run in the afternoon, then get in the RV (a 29-foot El Monte, which Kailey enjoyed very much and Michelle, not quite so much) and drive to the next destination.

"People always ask me if I got to see much of the country," Tim says. "Not really—unless you count looking out the RV window at night."

Training for the Distance

So how does a runner prepare to run that many miles in that few days? Tim wasn't too concerned. He worked with an exercise physiologist at Stanford University in the couple of months preceding the A-T Cure Tour to establish some guidelines and make sure he was capable of completing the effort. But Tim has been running for 11 years. He ran cross-country in junior college and worked his way up to triathlons (a 2.4-mile swim, a 112-mile bike ride and a 26.2-mile run), including the famous Ironman Triathlon in Hawaii. Then Tim competed in ultra-running events, at distances as long as 50 miles. This was pretty impressive for a man, says Tim, who started running in high school because he was overweight.

Given this background, running 26.2 miles a day is not ➤



as difficult as it seems. This is not to say it's just another daily training run, but the actual running was not the most challenging aspect of the A-T Cure Tour. Much of it was mental, to be able to handle the monotony—running, driving, sleeping and then running, driving and sleeping again. The key there, he says, was focusing on his goal, and it didn't hurt that his family was with him.

"Michelle has been incredibly supportive," Tim says. "She made a lot of sacrifices to do this, and I know I couldn't have done it on my own."

Some of the challenge was physical, but not from sore joints, painful knees or other running ailments. Tim, in fact, says that he has been remarkably lucky, and has not suffered anything like that during his running career. The bigger challenge was finding a way to keep weight

on, since all that running meant that he burned 3,000 calories more a day than normal. Tim started out with a scientific eating regimen, but by the end of the A-T Cure Tour, he was eating to survive. "I became a human garbage disposal. I wasn't eating because I liked it, but because I had to, and it almost wasn't fun to eat anymore," Tim says. All told, he was cramming down fatty foods, smearing mayonnaise on everything and consuming 7,000 calories a day—more than three times the average daily consumption.

Making a Difference

And now that Tim has finished the A-T Cure Tour? "We're just tickled about how it went," says Jennifer Thornton, the executive director of the A-T Children's Project, which put the Cure Tour together in conjunction with presenting sponsor Octapharma USA. "It's just incredible how we can increase awareness with a grass-roots effort like this. We've never had to field this many calls from the national and local media," continues Thornton, who notes that Tim appeared on ABC's "Good Morning America" and National Public Radio. "When they told me that Good 'Morning America' was calling, I thought the people in the office were kidding me."

In the end, running 63 marathons in 63 days was about getting that sort of attention for A-T and the kids who suffer with it. It was about raising money to support research to work for a cure.

"These people needed national awareness," says Tim. "It's not that people don't want to help. It's that they don't know about it. I felt called to match my focus and my purpose with their passion and their purpose."

Which he did—63 times in 63 days. ■

About A-T

Very little is known about ataxia telangiectasia, other than it is almost always deadly, killing children in their teens and early 20s. A-T is a rare, childhood neurological disorder that causes degeneration in the part of the brain that controls motor movements and speech. The first signs of the disease appear before the child is 10, and include delayed development of motor skills, poor balance, slurred speech and telangiectasia—tiny, red spider veins that sometimes appear in the corners of the eyes or on the surface of the ears and cheeks.

A-T can result in cancer, including leukemia. Many children with A-T develop weakened immune systems. If that's the case, IVIG is

often administered, and it does seem to help with that symptom of the disease.

About one in 40,000 babies is born with A-T. But some researchers think that number is low, because children with A-T may die before they are diagnosed.

For more information:

A-T Children's Project: www.atcp.org

NINDS A-T Information Page: www.ninds.nih.gov/disorders/a_t/a-t.htm



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.

For this column, I interviewed Andy, 22, and his mother, Stacy. Andy has ataxia telangiectasia (A-T). Andy's sister, Cassy, died due to complications of A-T in November 2005.

Shirley: Tell me about Andy's illness.

Stacy: Andy has A-T, a rare inherited disease that affects physical abilities and can affect the immune system. Andy's older sister, Cassy, had this disease also and her immune system was compromised so she required IMG. Andy's immune system is normal, he uses a wheelchair, his speech is unclear and he requires help using the computer. He swims and lifts weights to keep strong. He is an advocate for persons with disabilities. He works with ARC. ... Andy gives talks about fulfilling dreams for disabled persons at conferences and raises funds for A-T. He participated in their January 2007 Walt Disney World Weekend Marathon. He is very social and has a lot of friends. He is involved in church and youth groups. He loves the computer and has a site on MySpace. What's the address, Andy?

Andy: www.myspace.com/wheelchair_dude18.

Shirley: You've both had a hard time. I'm so sorry about Andy's sister. The diagnostic process must have been hard.

Stacy: Yes, it was long and difficult.

Cassy was 4, Andy 3. They were diagnosed at the same time. It took almost three years.

Shirley: Oh my, and now Andy is 22. Has he finished school?

Stacy: Yes, he graduated from high school in 2005. He celebrated graduation with skydiving. Now he is focusing on advocacy and fund raising. Another goal is to get a job. A group called "Work Opportunities" is helping him. Currently he is interviewing at movie theaters.

Shirley: Wow! Do you have anything else you can share with us that our readers might like to know about your family?

Stacy: Andy's brother, Taylor, 16, does not have A-T. When Andy needs help on the computer, Taylor is best. He learned a lot about life from his brother and sister. One more thing, I've been blessed with three wonderful children. Cassy and Andy have a spirit bigger than life. They inspire so many other people.

Andy: God put me here for a reason. That is to help others fulfill their dreams.

Stacy: Did you hear that?

Shirley: Sure did—wow!

Stacy: I told you he is amazing!

After I spoke to Andy and Stacy, I looked at Andy's MySpace site. This is his "About Me" message:

"My name is Andy Lutzenheiser and I am a pretty funny guy who loves to laugh with others and about myself.

I went skydiving July 9th 2005 and I raised over \$1000 for AT Children's project, it was awesome!! I hope to do it again next summer if I can save up enough money. I may be in a wheelchair but I love life, experiencing new things and meeting new people."

As Stacy says, Andy is amazing! ■

Resources

Ataxia telangiectasia (A-T) is a progressive, degenerative disease that affects many body systems. Children appear normal at birth and the first signs usually appear in the second year of life. Children affected by A-T are wobbly, caused by lack of balance, and have slurred speech. Both are caused by ataxia, which is a lack of muscle control. Telangiectasia, tiny red spider veins, usually appear shortly after the onset of the ataxia. Approximately 70 percent of children with A-T also have immune deficiency. A-T is a recessive genetic disease. Although parents do not exhibit symptoms, they do carry the gene that may cause A-T in their children. Each time two carriers have a child, there is a 25 percent risk that the child will have A-T. Healthy children have a 66 percent chance of carrying the gene. For more information, visit the A-T Children's Project website at www.communityatcp.org.

A-T Children's Project

668 S. Military Trail • Deerfield Beach, FL 33442
800-5-HELP-A-T • (954) 481-6611
info@atcp.org • jennifer@atcp.org

THE ART OF PAIN

By Zachary Pugh

From the surrealistic symbolism of Frida Kahlo to the serene lily ponds and landscapes of Claude Monet, artists throughout the ages have been influenced by chronic pain, illness and disability. In Kahlo's case, it was childhood polio followed by a bus accident when she was 18 that left her with severe chronic back and leg pain throughout her life. Experts claim Monet's art was largely influenced by cataracts on his retina, which coincidentally contributed to his famed impressionistic style.

For modern-day artist Jay Lloyd of Florida, chronic chest wall pain as a result of sarcoidosis was one of the driving forces behind his enigmatic creation, "Nerve Endings?"

Jay's Story

In 1996, Jay was diagnosed with sarcoidosis, an immune system disorder characterized by organ inflammation, often targeting the lungs. According to the Mayo Clinic, sarcoidosis is caused by an abnormal immune response, although the triggering factor is unknown.

Typically, sarcoidosis inflames the lymph nodes in soft tissue organs. "It can be in your bone marrow, it can be in joints, it can be in any soft tissue—lungs, kidneys, brain," Jay says. "What happened with me was that my lymph nodes swelled up in my chest so much that it actually pushed my chest out and put pressure on the nerves in my chest and either pinched a nerve or crushed a nerve.

"Sarcoid makes me sick all of the time, like once a month or every few weeks. It doesn't come with any regularity, but it makes me sick," Jay says. "You feel like you have the flu, you run a fever, you get nauseous, you're throwing up, you're achy. It's just a rotten thing to have. And there's nothing you can do for it except treat the symptoms."

Jay's treatment has ranged from steroids to surgery—all ultimately unsuccessful and resulting in the same conclusion: chronic chest wall pain. "Way back in '96,



"Nerve Endings?" by Jay Lloyd

they had a different way of thinking about it," he says. "They would bomb you with steroids. In the hospital, I was getting 60 to 80 to 90 milligrams. When I got home, I was on 50 milligrams. And you were stuck on [this] maintenance dose for the rest of your life."

Jay became increasingly frustrated as his treatment ordeal continued. "It was very upsetting, the doctors weren't telling me what was going on. They wanted to do test after test, without confirming what the previous test did. They ended up doing a mediastinoscopy where they cut your Adam's apple, go into your lungs and take the biopsy out. I've had the bronchiolavage. I've had radiation, total body scans, just about every test they could think of."

Seeking help, he called Johns Hopkins Hospital, and world-renowned lung disease expert Dr. Carol Johnson Johns reviewed the procedures he had gone through. She promptly referred him to a specialist at the hospital. "She was just really great, told me what to do."

Dr. Johns passed away in early 2000, but thanks to her vast knowledge and commitment to helping people, Jay's situation is much better than when he was first diagnosed. At her direction, he stopped taking steroids, slowly decreasing his intake over a two-year period.

Although he's now on an alternative treatment that seems to be working well, the pain still comes in waves. "The pain never went away. It was like someone sticking a knife in sideways in one of my ribs, and it went from front to back. It went in the front and came out of my back. And it still does, I can still feel it if I have a bad day or if the sarcoid flares up, which it does about every month."

Jay's Sculpture

When Jay first was inspired to create his sculpture, "Nerve Endings?," he was suffering complications as a result of treatment. "It's kind of strange because I was gathering up the pieces and I was looking for keys, marbles and different things, and then I found these plastic shards. Whatever the reason was, it seemed to fit. And then once I got all the pieces together, it probably took another couple weeks to do it.

"A lot of people see different things in it and it seems to help them," he says. "It wasn't something that I could focus on instead of [the pain], but it was something that came out of it."

Jay remembers vividly what it was like creating his sculpture. "Everything was on hold. I couldn't leave the house, I couldn't go from the bedroom to the living room without being winded and really in a lot of pain. I think that thing was something that I could control," he says.

"While I was working on it, I was in a lot of pain. I was sweating and I was hurting really bad. I'd work on it for a little while until I could not stand it and I'd stop. But it was like, 'I got to do this thing.'

"It wasn't really a way to express the pain, but I think it came out like that. Why these pointy shards? Why the keys? I don't know," he says. "I have people ask me, 'Why did you do this?' I don't know. It just fit at the time."

And the keys? "The keys are blanks. They're uncut. They had to be uncut. It was something that I had a little bit of control over because I had control over nothing else. And I think that's maybe why people [with chronic pain] do art—because they can have just that tiny little bit of control. They get that back."

Jay urges others who are learning to cope with chronic pain to divert that pain into something else, something positive. For Jay, self-expression through sculpture isn't a panacea, but it helps sustain him through his most painful struggles. ■



Artist Jay Lloyd

Resources

Visit HealthCentral's ChronicPainConnection.com, www.healthcentral.com/chronic-pain, a networking and resource website for people living with chronic pain, for more examples of pain art.

The Adventures of Itchy and Runny

By Cheryl L. Haggard

"Who's going to take care of me?" I screamed at my husband, Mark. His look of frustration confirmed his worst fear: I had gotten it.

What was it? Cryptosporidium.

The microscopic parasite that had terrorized my immune-compromised family's bowels and bathrooms had finally found its way to my ripe intestinal tract. Silly me, believing I was above such peasant-like infections. Crypto doesn't discriminate, especially against a mom of PIDD kids.

So, as I assumed the fetal position after blistering my husband with my worrisome plea, I wondered if I was going to be able to make my son Calvin's PB-and-J without a mid-making detour to the bathroom.

Then, with perfect immune-deficient timing, our son Caleb's crypto experience miraculously morphed into an abscessed tooth, which resulted in the need for minor oral surgery. I must say, it was quite entertaining trying to schedule a minor procedure for my PIDD kid while running to and from the commode to take care of my own business.

"What's that whooshing sound?" the insurance representative asked from the other end of the phone line.

"Oh, I'm sorry," I responded quickly. "I just started a load of laundry. I'm really quite amazed at what I can accomplish while scheduling surgeries for my kids!"

I literally didn't have the guts to tell her the truth.

Surgery day for Caleb greeted me with the buzz of the alarm clock and turmoil from my nether regions. It is not unusual for me to feel a pit in my stomach on my kids' procedure days; it comes with the territory. But this time my ill feelings were not caused by gnawing concern; rather, a mutant parasite was playing dodge ball with my duodenum.

As Caleb and I made our way to the surgery center, I pleaded with my Maker. "Just get me to the hospital without spontaneously combusting."

Funny, the last time I raced to the hospital with Caleb,

I was trying not to spontaneously give birth to him in the back of our vintage Volkswagen.

Once again, Caleb and I made it to the hospital successfully, with all body parts intact. But the triage nurse took one look at me and said, "Maybe we'd better put you in a suite with your own bathroom."

"Yeah, I'm not holding my gut because I missed my morning muffin," I quipped. "It's crypto."

"Ah, the love is spreading, huh?" she laughed.

Our nurse escorted us to a private room where I had the opportunity to buddy-up with some fresh porcelain.

As I emerged from meeting my new best friend, Caleb was rattling off his current medical history with the anesthesiologist. I listened carefully and nodded in approval when the doctor turned to me and asked, "Is he for real?"

Caleb shot back, "My mom's real sick right now, and it's my turn to take care of her."

I didn't want to cry because I was on the edge of dehydration, but I managed a whimper of pride as they rolled my hero away.

Caleb's surgery went without a hitch—until he began to itch. Something caused his already confused immune system to overreact, and his skin began to resemble a topographic map I studied back in junior high. As we raced toward home, I was desperate to keep my insides in, while worrying about Caleb's outsides falling off.

A quick phone call to our primary physician to schedule an impromptu appointment allowed us just enough time to make a pit stop at home.

Then, out of nowhere, a ridiculous request rolled off of Caleb's tongue:

"Mom, can I drive the rest of the way?"

His question snapped me out of the medical fog I was in.

"You just had surgery, you're breaking out in hives, and I really need to, well, you know."

"That's why it'd be fun!" Caleb chirped.

I then began a painful personal debate as to who was the safer driver: Itchy or Runny?

I slipped into my childhood for a moment and was whisked away to the comfort of sitting on my grandfather's lap as we drove his classic Mustang. The decision had been made, and there was no turning back.

As we passed the entry of our subdivision, I pulled to the curb and set my seat as far back as it would go. A smile grew on Caleb's face as I gestured for him to join me in the driver's seat. Caleb slid onto my lap and placed his swollen hands around the steering wheel. I prayed that we'd get home safely as Caleb's grin grew into whoops and hollers, echoing down our street.

Thirty minutes later, Itchy and Runny were telling our doctor about the day's adventures. And as the doctor was handing me Caleb's prescription, he voiced his opinion about my own pathetic condition. "You don't look so good yourself. Is there someone who can take care of you or can we call someone to drive you guys home?" our doctor asked.

Caleb and I looked deeply at each other, solidifying our recent illegal bonding experience.

"Don't worry about me," I promised our doctor as I shot a confident wink in Caleb's direction. "Itchy is going to take good care of his Runny." ■



ASK KRIS



Kris McFalls has two adult sons with chronic diseases treated with IG and is also on IVIG therapy 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.

Glinda: I am interested in research on long-term effects on the body of IVIG treatment. Do you know of any studies I can read? I am also interested in finding out more information about common variable immune deficiency (CVID). I am just grasping for information that is easy to obtain via the Internet and also here in my local area of Kentucky.

Kris: I've asked a couple of physicians to comment on long-term side effects of IVIG treatments. The concerns seem to stem around how treatment affects the kidneys. However, there is not a great deal of information on the long-term use of IVIG.

Dr. Hans D. Ochs, professor of pediatrics and Jeffrey Modell chair of pediatric immunology research at Seattle Children's Hospital: The best-known complications from the use of IVIG are infections due to contaminated product, e.g., hepatitis C. This is, however, very rare and limited to HepC. Mad cow disease [Creutzfeldt-Jakob disease] and HIV have not been transmitted. IVIG has been reported to cause aseptic meningitis, thrombosis, myocardial infarction and renal failure—most likely due to hyperosmolality of the preparation. If it has other side effects, they are unknown.

Dr. Richard Schiff, global medical director for Baxter Healthcare: There aren't a lot of long-term studies that have been done, especially for efficacy. However, Octapharma has done a long-term safety and tolerability study (available at www.igliving.com/web_pages/resources_news.html).

The following are resources with more detailed information:

- This is a letter to physicians from the FDA about the potential risk of renal failure associated with IVIG. www.fda.gov/medwatch/safety/1998/igiv.htm
- This is an FDA statement on the transmission risk of Creutzfeldt-Jakob disease, commonly known as mad cow disease. www.fda.gov/cber/blood/vcjdrisk.htm
- This is a patient notification system for which you can register to receive any recalls of immune globulin (IG) products. www.patientnotificationsystem.org

LaMeka: My doctor would like me to start IVIG treatment for CIDP, but I'm worried and would like more information about how it works, other people's experiences with this treatment, and homecare.

Kris: First, it is important to keep an infusion log of all your IG treatments. For a free infusion log, visit www.nufactor.com/pages/ig.html, select the Free Infusion Log Download from the Immune Globulin Resources menu and fill out the request form. You might also like to ask for the free emergency medical identification card. It is a driver's license-sized card that lists your disease state, medications, allergies, etc. You will receive two copies of the card, and they can be updated for free whenever you need.

Next, it's important to remember that asking your health-care provider, or a homecare company, about homecare does not mean you have to commit to it. It is good, however, to know what your options are. Homecare should first be discussed with your doctor to determine if you are a good candidate. The decision of where and how to treat is a personal one and should be based on what

you and your doctor feel is best for you—not what you read on the chat boards.

Please visit our CIDP Resources page at www.igliving.com. You'll find links to lots of websites with lots of information!

There are also "Frequent Flier" programs offered by some of the manufacturers for users of immune globulin. The product you use is made by Baxter, which has a program called Gamma Assist. You can sign up for it at www.immunedisease.com/US/patients/index.html. Do not worry that the website is for patients with primary immune deficiency diseases. I have checked with Baxter, and patients with CIDP can sign up for the program.

Reader: I want to see helpful hints for visiting crowded functions, how to say hello without skin-to-skin contact and how to greet a child meaningfully, but without hugging.

Kris: One of my favorite people provided a really thoughtful—and entertaining—response to this one.

Troy R. Torgerson, MD, PhD, attending physician, pediatric immunology/rheumatology at the University of Washington and Children's Hospital: Avoiding contact is a bit overboard. Most viruses and bacteria are transmitted via a hand-to-mouth route, so meticulous hand washing, frequent use of a hand sanitizer (there are all sorts of little bottles and tubes available that can be discreetly put in your pocket or purse and used almost without being noticed), and avoiding touching of your hands to your mouth, nose, eyes and face will go a very long way toward preventing transmission of organisms. Women can also get away with wearing gloves and telling people they are trying to keep their hands warm—guys just look like Michael Jackson wannabes. If you know that someone is overtly ill—stay away or hail him or her from across the room. You can tell them you are trying to avoid cooties (or bugs or whatever you want to call them). Life is pretty miserable without hugs from kids, so if they're sick, just give them a squeeze or tousle their hair—and then use the hand sanitizer!

Kimberly: My son Brian's immunologist gave him a flu shot and wants to do a TB test and other tests, and then do more blood work in four weeks—something regarding his T cells. We're going to Children's Hospital, but I'm not sure what test to ask for there for a quicker diagnosis.

If Brian is a candidate for IG therapy, I would really like to understand why—or why not. I'm tired of living in limbo!

Kris: A solid understanding of how the human immune system works will help you better understand the tests your physician recommends. We have a great family-friendly immune system presentation, by Dr. Troy Torgerson, you can download from www.igliving.com/web_pages/resources_niceday.html.

It sounds as though your son's physician is trying to better understand how your son's T cells and B cells are functioning. Many of these tests must be done before your son begins treatment. Understanding how his T cells and B cells function prior to treatment will also give the doctors a better understanding of what kind of prognosis to expect from treatment and any necessary precautions that need to be taken.

I know how hard it is to see your son sick. When my son was diagnosed more than 17 years ago, I wanted the treatment for him. I didn't understand what it was, I didn't even realize it was an infusion, I just heard the doctor tell me there was a treatment that would help—and I wanted it for my son. Looking back, it would have been smarter to have had more information before we began treatment.

So much progress has been made in the field of immunology since my boys were diagnosed, but insurance companies have become more rigorous in their review of requests for IG treatment. Consequently, doctors often request what may seem like a lot of tests, but they use the results, along with other clinical data, to back up their recommendations for IG treatment.

The information you get now is valuable to your son's treatment long term. Bring a list of questions to your son's next appointment. Ask the doctor what makes your son a good candidate for treatment, and ask for a timeline for what to expect leading up to an ultimate treatment decision.

I consulted with Dr. Schiff, and he added a few thoughts:

Dr. Schiff: If this child is of school age and has an IgG level < 300 with recurrent infections, it sounds to me as though he may need IVIG, regardless of whether he has a T cell response. In addition to asking questions, encourage Kimberly to make sure she understands the answers before she leaves the appointment. If she doesn't, she should ask more questions or get another opinion. ■

Send your IG therapy questions to editor@igliving.com or visit Ask Kris at www.igliving.com.

Nutrition for Sick Days

By Jessica Schulman, PhD, MPH, RD

“Infections, no matter how mild, have adverse effects on nutritional status. The significance of these effects depends on the previous nutritional status of the individual, the nature and duration of the infection, and the diet during the recovery period.”¹

Most people caring for a sick loved one have heard the old myth: “Feed a cold, starve a fever.” But another version of the myth touts just the opposite: “Starve a cold, feed a fever.” Neither version is good advice. Starving an individual with a virus, and thus depriving the body of fluids, can bring on the fever that this practice was meant to prevent. Also, nutrition requirements generally increase when you get sick, so it is important to eat as well as you can—not starving or stuffing—during infections.

Any illness, mild or severe, can exacerbate existing nutrient deficiencies. For example, in children who have borderline levels of iron, infections generally trigger anemia. Those who have suffered with recurrent infections are more vulnerable to the cycle of poor nutrition and delayed healing when the next infection strikes. This article provides some basic rationale and tips for promoting healing and eating well during uncomplicated infections.

Feed the Cold, Feed It Well

When individuals are sick, energy or caloric needs are higher than when they are well. To determine your basal metabolic rate (which does not factor in fitness level or infection), refer to Cornell University’s Medical Calculator: www-users.med.cornell.edu/~spon/picu/calc/beecalc.htm. In general, metabolic rate increases 7 percent for each Fahrenheit degree increase over normal. Depending on the severity of the illness, increased metabolic demands can increase energy requirements by 20 percent to 60 percent. For these reasons, encourage sensible eating if an individual with a fever has an appetite—or try to find creative ways to provide nutrition.

During or immediately after an infection, avoid dieting and trying to lose weight. The body responds differently

to stress due to eating less and exercising than it does to energy restriction during an infection. During an infection, more calories (about 30 percent) come from the breakdown of muscle or protein stores. During healthy periods, dieting and exercise cause the majority of calories (about 90 percent) to come from the burning of fat stores and only a marginal amount of calories from the breakdown of protein.

What does this mean? Preventing weight loss during infections will help you to preserve muscle mass and support the critical role that proteins have in health and disease.

Not by Bread Alone

The concept of increased metabolism and protein needs during infection dates from the 19th century.² Today, scientists report that individuals need about .8 gram of protein per kilogram of body weight per day. For a 150-pound adult, this equates to about 55 grams of protein each day. Food labels provide the number of grams of protein in each serving of an item, so it is easy to add up the number of grams of protein consumed in one day. During an infection, however, you may require as much as 1.2 to 2.0 grams of protein per kilogram of body weight per day to limit breakdown of muscle stores in the body. For a 150-pound adult battling a severe or chronic infection such as HIV, this can easily double the protein requirements to about 100 grams. Higher protein diets (> 1.0 gram per kilogram) are not usually needed for run-of-the-mill upper respiratory infections. Always consult with your physician before starting a high protein diet.

Adequate calories from carbohydrates are also needed for your body to use protein efficiently during infections. In 1909, Shaffer and Coleman found that they could reduce, and even eliminate, protein breakdown during an infection when patients consumed diets high in calories with protein.³ Today, we know that without adequate total energy intake, protein stores will not be preserved during illness. This effect becomes more pronounced during severe or ongoing infections.

¹ Scrimshaw NS, SanGiovanni JP. Synergism of nutrition, infection, and immunity: an overview. *Am J Clin Nutr.* 1997; 66:464S-477S.

² Keusch, GT. The history of nutrition: Malnutrition, infection and immunity. *J of Nutr.* 2003; Jan 133:336S-340S.

³ Beisel WR, Powanda MC. Symposium: Nutrition and Infection, Prologue and Progress Since 1968 Metabolic Effects of Infection on Protein and Energy Status. *J of Nutr.* 2003; Jan 133:322S-327S.



In the 1960s, W.R. Beisel and his colleagues at the U.S. Army Medical Research

Institute of Infectious Diseases

studied how the body responds to infections.³ Volunteers were given infections that varied in severity and their nutrition status was monitored. All were offered normal amounts of dietary protein and calories. Volunteers who were exposed to the least severe infection—and suffered only three days of fever—still took 10 to 11 days to recover from the breakdown of protein. The results from this study underscore the importance of getting adequate protein and calorie intake during fever and recovery. This is good news for those who enjoy protein and carbohydrate-rich comfort foods, such as homemade macaroni and cheese or chicken noodle soup when they are sick.

Pamper the Palate

Infections or certain therapies can cause mouth sores, sensitive gums and sore throat, all of which can make eating an unpleasant experience. Your doctor can suggest appropriate remedies for these symptoms, such as topical sprays that can help you get through a meal. In addition, try to consume foods that are easy to chew and swallow. Milkshakes or smoothies supplemented with nutrient-rich foods, such as banana and soy powder, may be more easily tolerated. Always check labels and make sure these foods are consistent with your treatment plan. Other soft food favorites include plain bananas, apple sauce, ripe pears, yogurt, mashed potatoes, pasta, gelatin, rice pudding, scrambled eggs, cooked cereals, well-cooked carrots and other veggies, fish and ground meats with extra sauce. Avoid acidic citrus fruits and coarse dry items such as a toasted sandwich. Foods should be cooked until tender and eaten cold or at room temperature. Mix small bites of food with apple sauce, butter, gravy and salad dressings to make them easier to chew and swallow.

Tempt the Taste Buds

During an infection and the recovery period, one should try to consume foods that are balanced. Of course, this is easier said than done. It is very common to lose interest in food when one has an infection. When you get sick, inflammatory cells, such as neutrophils, granulocytes and macrophages, are called to action. They secrete cytokines, like interleukins IL-1, IL-6, IL-8, and tumor necrosis factor (TNF- α), that cause the body to break down protein into amino acids. This fuels acute-phase proteins such as C-reactive protein, mannose-binding protein, alpha 1-antitrypsin, coagulation factors, etc., that loot your nutrient stores. How does this make you feel? Icky.

Negative nitrogen balance, a consequence of the breakdown of protein, starts with a fever and persists for days or weeks after the fever has ended. So, it is very important to try to prepare or purchase nutrient-rich foods with more protein bang for the buck. Legumes, meat, chicken or fish might be more palatable by marinating them in teriyaki sauce, sweet wine, mango salsa, etc. Try to prepare foods that look and smell good to you—even if it means eating oatmeal for dinner and a chocolate smoothie for breakfast. If you are worried about the claim, “milk makes mucus,” do not despair. Unless you have a food allergy or intolerance, there is no reason to avoid dairy. Pinnock, et al. (1990) gave volunteers rhinovirus and then monitored their respiratory symptoms and mucus secretions.⁴ Milk and dairy product intake was not associated with an increase in respiratory tract symptoms of congestion.

Sidestep the Schnoz

Illness and medications can alter your sense of taste and smell, with the possible consequence of making health-promoting food seem less appetizing. If possible, avoid the kitchen when food is being prepared and try foods that have low odors. For example, cold cereals, smoothies and French toast do not require long cooking times or much preparation. Sometimes it helps to eat foods that are cold, to lessen the aromatic compounds that migrate up the sneezer. To test this, place an onion in your fridge before chopping it up. To further minimize ➤

⁴ Pinnock CB, Graham NM, Mylavaganam A, Douglas RM. Relationship between milk intake and mucus production in adult volunteers challenged with rhinovirus-2. *Am Rev Respir Dis*. 1990 Feb; 141(2):352-356.

smells, put drinkables in cups with lids and try using a straw or sippy cup.

If Blandness Is the Problem:

- Try flavoring foods with more potent ingredients such as garlic, basil, ketchup, relish, mustard, etc.
- Flavor a shake with vanilla extract, decaffeinated coffee or a few ounces of your favorite nutrition supplement such as caramel pecan Muscle Milk®, chocolate Ensure®, orange cream PediaSure®.
- For those on elemental diets, such as Neocate® or Vivonex®, specialized flavor packets are available (for more info, visit www.nutriciahealth.net/index.htm).
- Some patients may be able to tolerate homemade flavor packets, made by adding a pinch of coconut or raspberry extract with a few teaspoons of their favorite flavor of Kool-Aid® or Crystal Light®.

Wet Your Whistle

The body's ability to detect thirst is dampened by certain medications and infections. For these reasons, dehydration is more likely to occur during infections because either the individual is not getting enough fluid or they are losing excess water through sweat, stool, urine or vomit. This, coupled with the notorious "lost appetite," reduces fluid intake further. If you have a fever, this can be a dangerous combination. The following scenario illustrates the risk.

Brian came home from work early. He felt feverish, tired and generally cruddy. By the time Vicki arrived home, she was unable to rouse him and called the paramedics. At the hospital, after Brian received intravenous fluids, he woke up but was still very confused and lethargic. When Vicki asked what happened, he said, "I didn't feel well and I was really tired, so I thought I'd take some medicine and go to sleep." What Brian didn't realize was that he was dehydrated, and going to sleep without fluids only made things worse. Brian was lucky to have received emergency medical care.

What might Brian have done differently? If he had heeded the initial signs of an infection and begun to consume fluids early on in the course of the illness, he could have escaped the serious consequences of dehydration.

Fluid imbalances cause problems during infection and exacerbate symptoms. Mild dehydration (as little as 1 to 2 percent loss of body weight, i.e., 1.5 pounds of fluid loss for a 150-pound individual) contributes to confusion, headache, weakness, dizziness, fatigue, muscle weakness, low blood pressure, rapid heartbeat and fever.

Yes, fever causes fluid loss, which can then cause an even higher fever. When you are dehydrated, blood flow to your skin is lessened and you don't perspire and cool down effectively. Then your temperature goes up!

How do you know if you are getting enough fluids during an infection? Under normal conditions, about 6.3 cups of fluid are lost each day simply by living and breathing (2.5 cups per day are lost through the skin, 1.7 cups are exhaled through the lungs, and 2.1 cups are lost in urine). About 2 to 4 additional cups per day are needed for a moderately active adult. Extra water is needed when one has a fever, infection, diarrhea or vomiting. As a rule of thumb, the need for water increases by about one-half cup for each degree rise in body temperature over normal. For example, if Brian's temperature was 101.6° Fahrenheit, he would need about 1.5 extra cups of water ($101.6^{\circ} - 98.6^{\circ} = 3^{\circ} \times .5 \text{ cup}$).

However, counting cups of fluid consumed is not always useful. A decent gauge of your hydration status is the color of your urine. Clear or light-colored urine usually means you are well hydrated. Amber-colored or smelly urine typically means that the urine is too concentrated. Plain water, salty broths, concentrated fruit juice drinks are generally not recommended for dehydration or diarrhea, but are usually well tolerated for uncomplicated respiratory infections. Excellent choices include frozen Pedialyte® sticks, juice bars, flavored water, unsweetened tea, diluted fruit juice with a pinch of salt and soups.

For diarrhea and vomiting, the doctor may suggest a special solution that contains sugar and electrolytes. The body needs glucose to absorb electrolytes and keep the body hydrated—one molecule of glucose will transport two molecules of sodium into the cells. In one study,



Pedialyte® and Gatorade® were shown to be effective and safe for treating mild dehydration among patients with normal blood electrolyte values.⁵ Small sips of a rehydration solution at frequent intervals are advisable. Rapid hydration is not feasible in certain patient groups, like those with low sodium levels or critically ill patients. Diarrhea or vomiting that comes on suddenly can lead to rapid loss of water and electrolytes. This form of dehydration is difficult to manage and a doctor should be consulted. Severe dehydration must be treated immediately in a medical setting.

Mind Over Matter, Food as Medicine

Nutrition is important during infection and recovery, but what if you just don't feel like eating? Sometimes, it can help to make other adjustments in the social or physical environment. For example, use a smaller-than-usual spoon (even a baby spoon). Take as much time as necessary to eat the meal. Try to make the eating environment calm and inviting. If you are not sitting at a table, be sure to sit in an upright position. A good trick to use with children, or adults, is having a "backwards food day." Perhaps eating the more difficult nutrient-dense foods, such as chicken soup and a sandwich, in the morning when you feel rested, and the easier foods, like pancakes, in the evening when fatigue and fever may be worse. Keep in mind that food will soon be enjoyable again but, for the time being, adopt the wisdom of Hippocrates, "Let food be thy medicine, and let thy medicine be food."

Coax Small Appetites

If your child is sick, make sure he or she consumes adequate calories and protein for healing. If your child's appetite is impaired, think about adding extra nutrient-rich foods when possible. For a child with no dietary restrictions, consider topping fruit with cottage cheese, spreading peanut butter on crackers or tearing out a half-dollar sized hole in a piece of bread and frying an egg in it. I've managed to get many "eggs in a hole" into my picky kindergartner on sick days (that is, if I smother them in butter and jam).

If a child or adult is not interested in foods you have

prepared, consider offering a few choices of familiar comfort foods. Small meals and nourishing snacks may be better tolerated. Sick days are not the right time to enforce behavioral changes at the table. Create a pleasant eating environment so the patient does not feel pressured to eat. When a child is not feeling well, try to stay calm and avoid power struggles. Be creative and add cooked and blended or grated vegetables to spaghetti sauce, soups or casseroles. A supplemental pediatric beverage may be useful in some situations.



Nursing Babies Back to Health

Breastfeeding rarely needs to be discontinued for infant illnesses. During a respiratory infection, babies' need for nutrition and comfort goes up and they may need to be nursed more frequently. Scientists have examined milk from breastfeeding mothers of infants hospitalized with bronchiolitis and compared them with the milk expressed from mothers of healthy infants.⁶ Milk from the mothers of infected infants was significantly higher in antibodies, antimicrobial fats, peptides, lactoferrin and other protective elements.

Sounds great, but how do you feed a baby who is coughing, plugged up and refusing to nurse? Try clearing the baby's nose with saline drops and a gentle suction ➤

⁵ Rao SSC, Summers RW, Rao GRS, Ramana S, et al. Oral rehydration for viral gastroenteritis in adults: A randomized, controlled trial of 3 solutions. *JPEN*. 2006; Sept/Oct; Vol.30, Iss.5; 433-439.

⁶ KByran DI, Hart PH, Forsyth KD, Gibson RA. Immunomodulatory constituents of human milk change in response to infant bronchiolitis. *Pediatr Allergy Immunol*. 2007; Sep;18(6):495-502.

before beginning to nurse. Sometimes, nursing in a steamy bathroom or waiting until the milk lets down before nursing can help. However, babies with an immune deficiency may require more assistance. Ask your child's doctor for the safest way to clear the baby's sniffer. Try feeding the baby expressed milk from a dropper, cup or spoon. Cool the milk down until it forms a slushy consistency and offer spoonfuls. Frozen breast milk, or "momsicles," can be useful to prevent dehydration. Babies older than 6 months may be able to tolerate breast milk thickened with baby food. Formula-fed babies may benefit from similar strategies.

Optimize Nutrition Status

Proper nutrition is particularly important for special groups who are healing, at risk of recurrent infections or

have less-than-ideal nutrition status. However, no amount of good nutrition will cure a primary immune deficiency disease (PIDD). Among children living with PIDD or other medical conditions, malnutrition often follows from the disease and not the reverse.⁷ Nevertheless, there is still a lot that patients and caregivers can do to optimize their dietary intake during infections—and benefit from an improved quality of life. ■

This article is intended for general informational purposes only. Individuals with chronic conditions should consult their physicians to determine what eating pattern is appropriate for them. Jessica Schulman 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.

⁷ Morgan G. What, if any, is the effect of malnutrition on immunological competence? *The Lancet*. 1997; Jun; 349(9066):1693-1696.

A New IVIG Coming in Early 2008



CSL Behring announced in July that the U.S. Food and Drug Administration (FDA) granted marketing approval for a new intravenous immune globulin (IVIG) product, Privigen. Privigen is approved for treating patients diagnosed with primary immune deficiency disease and for the treatment of chronic immune thrombocytopenic purpura (ITP) to rapidly raise platelet counts to prevent bleeding.

A 10-percent liquid preparation of polyvalent human immunoglobulin, Privigen offers healthcare professionals and patients convenience and ease-of-use because it requires no refrigeration or reconstitution.

"Privigen is an exciting new offering to patients and healthcare professionals in the United States," said Paul

Perreault, executive vice president of Worldwide Commercial Operations at CSL Behring. "As the leader in developing safe, high-quality, effective immune globulin therapies for use around the world, CSL Behring is proud to add yet another product to our rapidly growing portfolio. We see a strong demand for Privigen and are pleased to be bringing it to patients and other valued customers."

Dr. Mark Stein, chief of the allergy section at Good Samaritan Hospital in West Palm Beach, Fla., indicated that Privigen answers an important need. "The time savings and flexibility it provides to healthcare professionals is an important step forward. It will certainly be a welcome addition to currently available immune globulin therapy options in the U.S." Dr. Stein served as lead investigator on the Privigen clinical trial.

CSL Behring plans to launch Privigen in the first quarter of 2008. ■

Resource Directory

Ataxia Telangiectasia (A-T)

Websites

- A-T Children's Project: www.atcp.org
- NINDS A-T Information Page: www.ninds.nih.gov/disorders/a_t/a-t.htm

Chronic Inflammatory Demyelinating Polyneuropathy (CIPD)

Websites

- GBS/CIDP Foundation International: www.gbsfi.com
- National Institute of Neurological Disorders and Stroke (NINDS) Chronic Inflammatory Demyelinating Polyneuropathy (CIPD) Information Page www.ninds.nih.gov/disorders/cidp
- Neurology Muscular Dystrophy and Neuropathy Institute Illustration of a damaged myelin sheath on a nerve: www.beverlyhillsneurology.com/cidp

Online Peer Support Links

- The Neuropathy Association: www.neuropathy.org
- Barbara's CIDP/GBS Site (This is a personal website) www.geocities.com/HotSprings/Falls/3420

Evans syndrome

Websites

- Evans Syndrome Research and Support Group: www.evanssyndrome.org
- Office of Rare Diseases (catalog of online resources) <http://rarediseases.info.nih.gov/asp/diseases/diseaseinfo.asp?ID=6389>

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 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.pdsa.org
- National Heart, Lung and Blood Institute www.nhlbi.nih.gov/health/dci/Diseases/Itp/ITP_Whats.html

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
- 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

Multifocal Motor Neuropathy (MMN)

Websites

- National Institute of Neurological Disorders and Strokes (NINDS) provides a Multifocal Motor Neuropathy Information Page: www.ninds.nih.gov/disorders/multifocal_neuropathy/multifocal_neuropathy.htm
- Multifocal Motor Neuropathy Center at Johns Hopkins Department of Neurology www.neuro.jhmi.edu/MMN/index.html
- The Neuromuscular Center at Washington University in St. Louis, Mo. Neuromuscular Home Page www.neuro.wustl.edu/neuromuscular
- The Neuropathy Association is dedicated to helping those with conditions affecting peripheral nerves. www.neuropathy.org

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,” 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/rarediseasesp/al/pemphigus05.htm>

Peripheral Neuropathy (PN)

Websites

	<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.
- “Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won’t Stop” by Dr. Norman Latov, MD, PhD, published 2007, Weill Medical College, Cornell University, provides practical information on all the neuropathies, causes and treatments.

Primary Immune Deficiency Disease (PID)

Websites and Chat Rooms

	<p>The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is dedicated to improving the diagnosis and treatment of PID through research and education. 800-296-4433</p>
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<h3>Jeffrey Modell  Foundation</h3>	
<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>	

- 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 PID.
- The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PID patients.
- To connect to a PID 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 PID 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, PID 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.

Scleroderma

Websites

- Johns Hopkins Medicine Scleroderma Center: scleroderma.jhmi.edu
- Scleroderma Research Foundation: www.srfcure.org
- Scleroderma Foundation: www.scleroderma.org

Online Peer Support

- Educating instead of medicating CureZone.com <http://curezone.com/forums/f.asp?f=404>
- International Scleroderma Network www.sclero.org/support/forums/a-to-z.html

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.aininc.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
- Mayo Clinic
Stiff person syndrome: Can it be treated?
www.mayoclinic.com/health/stiff-person-syndrome/AN01377
- 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.kidshealth.org/parent/system/ill/seriously_ill.html.
- The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at www.ncqa.org.
- The nonprofit Patient Advocate Foundation, www.patientadvocate.org, seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274

	<p>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</p>
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- 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.
- American Chronic Pain Association (ACPA) was founded in 1980 to provide resources for people coping with chronic pain. www.theacpa.org

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 Breznsny, 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
- Food Allergy and Anaphylaxis Network: 800-929-4040 www.foodallergy.org
- World Allergy Organization: www.worldallergy.org
- Sicherer, S.H. (2006). "The Complete Peanut Allergy Handbook: Understanding and Managing Your Child's Food Allergies," Johns Hopkins Press.

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.

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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