

IG LIVING!

IMMUNE GLOBULIN COMMUNITY

www.IGLiving.com

June-July 2009

PIDD and Sinusitis

Understanding the Diagnoses and Treatments

Controlling IG Side Effects

An Overview of Plasma Derivatives

Insurance and Explanation of Benefits

GERD and Coughing in PIDD Patients

Indoor Green Environments for Healthy Living

U.S. \$3.00

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About *IG Living*

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

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Living with Side Effects



AS THE NEW editor of *IG Living*, let me first say that it is my pleasure to have joined this community. My experiences during these first months on the job have been eye-opening in many ways. I am learning just how prevalent autoimmune and primary immune diseases are, and just how unaware society is about the conditions that fall under these labels. Most importantly, I am learning about the “effects” of living with these conditions.

As you well know, unless personally affected by one of these diseases, it is impossible to understand what it means to be faced with both the disease and the lifetime of treatment. Being personally affected typically means that you are suffering from a condition yourself, or that you have a child or a loved one who is. Other relatives, friends and acquaintances can sympathize, but they may never really understand. I was a perfect example of this. Many years ago, my mother-in-law suffered from myasthenia gravis (MG), and I watched her succumb to the disease that only now I understand is an autoimmune disorder. Back then, I had never heard of autoimmune disorders, much less their effects on a person’s body. Just this past year, a friend of mine told me she had been diagnosed with rheumatoid arthritis (RA), but that it is treatable. At the time, that meant nothing to me; I had not understood what RA really is or what the effects of living with that disease will mean for her. Once again, it is only now as the editor of *IG Living* that I have a better understanding.

I recently had the pleasure of taking part in an *IG Living* readers teleforum. These conference calls, which are held one to two times per month, allow you, our readers, to share information about your conditions, offer advice to each other and even ask questions of our patient advocate, Kris McFalls. One of the main themes that recurred in the hour-long discussion was coping—coping with the lifestyle effects, such as health issues, and home and work life; the frus-

trating effects of understanding the disease, making others understand what you’re going through, and dealing with insurance hassles; and the side effects of medication.

Much of the content in this issue of *IG Living* is about “effects.” We look at the similarities between the causes and effects of immune deficiency and autoimmunity. Research is proving that the two aren’t as distinct as once thought. We also examine common side effects for IG patients, including sinusitis, GERD and IG medication reactions. Patients who suffer from sinusitis will benefit from understanding what causes this chronic condition and how they can avoid it. Those who are affected by GERD will find interest in the explanation of the symptoms, what the long-term consequences can be and what can be done to treat it. And, because there are often side effects from IG therapy, patients will appreciate knowing that there are ways they can manage them. In addition, we feature our regular lifestyle columns, written by our seasoned patients and caregivers, that provide you with useful facts, interesting stories, as well as some comic relief about the side effects of day-to-day IG living.

As always, while we strive to provide you with as much information to make your lifestyle as free from “effects” as possible, we appreciate hearing from you. Email me at editor@IGLiving.com to send me your comments about the magazine. And, feel free to make suggestions for topics you would like to read about in future issues. ■

To your health,

Ronale Tucker Rhodes, MS, Editor

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

A community service from
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Plasma Derivatives: An Overview

"Today, plasma derivatives are manufactured from human plasma by fractionation, a process used to isolate specific proteins needed to treat various diseases."



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Immune Deficiency and Autoimmune Disease: A Complicated Relationship

"Researchers are beginning to realize that there are a few key genes that are significant in both immunodeficiency and autoimmunity."



JENNIFER KESTER
Freelance Writer

PIDD Patients and Sinusitis

"Though each case is different, knowledge about a patient's particular form of sinusitis can empower them, and help to alleviate the recurring bouts of sinus infection."



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GERD and Coughing: What PIDD Patients Need to Know

"The majority of patients with GERD do not develop serious complications, especially if treated appropriately."



KRIS MCFALLS
IG Living Patient Advocate
NANCY CREADON, RN
Vice President, VaxAmerica

Side Effects of IG

"If a patient battles side effects, no matter what is done to reduce them, it may be time to try another brand or another method."



JIM TRAGESER
Freelance Writer

Reading and Understanding Your Explanation of Benefits

"While there is an understandable relief in seeing that it's not a bill, an EOB itself is an important document in managing our healthcare costs and lifetime benefit caps."

Connect with Other *IG Living* Readers through Monthly Teleforums!



IGL's Readers Group Teleforums allow readers to connect with others to share their experiences living with chronic diseases. Here's how you can participate:

- Email *IG Living* to be added to our email invitation list for the teleforums.
- *IG Living* will send you invitations to let you know when the two-per-month, hosted, toll-free teleforums will be held, as well as what topic relevant to the IG community will be discussed.
- The moderated, hour-long calls will be filled on a first-come, first-served basis and will be limited to 15 readers.

In addition to connecting with others, *IG Living's* patient advocate can help you determine if there's a patient organization support group in your area. Or, she can help you to start an IGL Readers Group of your own. To join a group or start one in your area, visit www.IGLiving.com and click on IGL Readers Groups.

Sign up for the Teleforums now by emailing kmcfalls@IGLiving.com or calling (888) 433-3888, ext. 1349.

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.

IG Living Kudos

Dear Editor,

I want to thank you so much for *IG Living* magazine. I save every issue! I just got mine today and can't wait to finish it. It is so helpful and informative, and wonderful for making us aware of different challenges and current legislation. It also opens our eyes to things we never would have known or thought about. And, it certainly does make it more of a "community" thing and less of an "overwhelming, I'm the only one out there, I don't know what to do" thing. Thank you so much for the work you do. You make it a lot easier for the rest of us!

—Rachel, Pennsylvania

I want to let your know that Kris McFalls, who writes the Ask Kris column, is such a wonderful person. You are lucky to have her working with your magazine. Kris responded to me after I started IVIG treatments and was looking into SubQ therapy. She was a wealth of information and gave me names of doctors in my area who know about SubQ therapy. I went to see one of those physicians, and he spent 45 minutes with me — went over my diagnosis, answered all my questions and just genuinely cared about my case. I would not have found him if it weren't for Kris' willingness and obvious concern and empathy for patients with immune deficiencies. I am so thankful for *IG Living* and for Kris!

—Peggy, Washington

Finding a Solution

Dear Editor,

I am 48 years old, and being diagnosed with primary immune deficiency a little over a year ago changed my life. I was ill on a regular basis for many years. I've been

through more doctors, medications and remedies than you could possibly imagine. For the past few years, I have had two sinus surgeries, periods of chronic bronchitis and pneumonia, and I was on prednisone and antibiotics. My quality of life had diminished to leaving the house for groceries only. At one point, I left a career of 17 years as a dental assistant in the Boston area because the doctor told me the "chemicals" were making me sick. I was so sick at that point, it took a year before I could really do much of anything.... I actually have had doctors tell me that I was going through "empty nest syndrome." One doctor told me when I was 34 years old that I wasn't doing what he told me to do....

Since my diagnosis, I feel so vindicated. How did this happen? I don't just mean to me, but to all the others out there who have had similar experiences with physicians. This shouldn't be happening in a country that has the medical knowledge we have. It makes me angry to think that I have had this all of my life, but it took this long to diagnose. I have had all the signs and symptoms of primary immune deficiency, which recently took less than \$200 to diagnose. So much of my life and money wasted....

I have become an active volunteer and [I have formed] a support group in Rhode Island.... Anchorwoman Barbara Morse on ABC's Turn to 10 interviewed me and another IDF member in Rhode Island to help raise awareness of PIDD. ■

—Susan, Rhode Island

Editor's note: We encourage all of our readers to take a proactive approach to help with the diagnoses and treatments of individuals in the IG Living community. The examples provided by Susan of ways to get involved are appreciated. Susan has formed a support group in Rhode Island, which can be accessed at rhodeislandpidd@yahoo.com.

ViroPharma Receives FDA Approval for Cinryze

By Catherine Billey

ViroPharma recently received approval for Cinryze, the first FDA-approved C1 inhibitor for treating hereditary angioedema (HAE) in this country. As the newest U.S. plasma-derived product, the entrance of Cinryze into the market represents 30 years of development.

HAE is a disease that is so rare, it often goes undiagnosed for years. Before an attack, patients will experience tightness or tingling where swelling later occurs, accompanied by a red blotchy rash, mood changes, anxiety and exhaustion. During the attack, hands, feet, face, arms and/or legs swell up, in some cases hideously. Internal swelling in the abdomen may cause pain, nausea and vomiting. Worst of all, swelling in the air passages may cause difficulty swallowing or even breathing.

The rare illness affects about 10,000 people in the United States, although Kristina M. Broadbelt, assistant director of public relations and advocacy at ViroPharma, said she has seen statistics indicating up to 30,000 individuals are affected. An HAE attack can strike suddenly and come on as rapidly as within four to five hours. "It is really a devastating disease. It truly affects quality of life," she said. "People can't travel, work and, oftentimes, can't go to school."

The C1 inhibitor product has been marketed in Europe as Ceter for 30 years. When ViroPharma acquired the biopharmaceutical company Lev in 2008, Lev had been developing the



drug to fulfill the unmet need for it in the United States. Dr. Ira Kalfus, vice president of medical affairs at ViroPharma, explained that "it's a drug for an orphan disease, so there isn't that large a market out there. It's difficult for drug companies to develop products for small numbers of patients."

Because HAE is so rare, it can be misdiagnosed in emergency rooms, where Benedryl and corticosteroids are often mistakenly prescribed. "Oftentimes, people present in the emergency room with very bad stomach pains—this can be in your extremities, your stomach, your genitals, your neck—and physicians don't know what it is," Broadbelt explained. "So there's been unnecessary exploratory gastrointestinal surgery—many unnecessary surgeries."

Dr. Glenn Tillotson, head of medical affairs for ViroPharma, estimates that about 30 percent of abdominal surgeries are unnecessary. He wants to encourage the use of computerized tomography (CT) in emergency rooms—a scan for people with surgical

belly (very large and requiring quick help) to ascertain whether the surgery is actually required. According to Tillotson, when patients present with a surgical belly, interns and surgeons "don't really [ask] the sort of background questions that could help prevent unnecessary surgery."

Kalfus confirmed that patients who suffer from HAE have a deficiency in the plasma protein called C1 inhibitor, which controls several of the inflammatory pathways and helps regulate them. "If these pathways get turned on, for whatever reason, the absence of C1 inhibitors makes it difficult for them to be shut off," Kalfus explained.

ViroPharma is approved for the Cinryze prophylaxis, which is about two or three doses a week, for HAE. "[Cinryze] raises the C1 inhibitors that are available in the circulation," Kalfus said. "So the theory is patients have these attacks because they're deficient in C1 inhibitor, and by raising your levels, you can prevent these attacks. We've demonstrated that we've reduced the frequency and severity of these attacks."

"The good thing is if you give someone Cinryze or C1, it inhibits those reactions within an hour," Tillotson said. "We've actually helped patients quicker than that, but I'd rather say the norm is about an hour's time." ■

CATHERINE BILLEY is a staff writer for the *Mammoth Times* and *Sierra Magazine* in Mammoth Lakes, Calif.

Editor's Note: For more information about HAE, go to www.hereditaryangioedema.com.

Research

Stroke and Heart Attack with IVIG Use Related to Risk Factors

Can IVIG cause a stroke or heart attack in elderly, hospitalized patients? A new study reveals that the risk of stroke and heart attack are increased only if patients have two or more cardiovascular risk factors.

The study, conducted by a team of Wake Forest University (Illinois) researchers and published in *Neurology*, looked at the medical records of 19 patients who had a stroke or heart attack after receiving IVIG, as well as the records of 38 patients who were the same ages who received IVIG treatment but did not have a stroke or heart attack. The patients' average age was 71 years, and they received IVIG treatment between August 1998 and May 2004. Gender, race, the reason for receiving IVIG treatment, dosage, previous exposure to the drug and the patients' risk factors for stroke and heart attack were all compared.

The researchers found that no single cardiovascular risk factor increased the

chance of having a stroke or heart attack after IVIG treatment. However, the likelihood did increase slightly when the patient had two or more risk factors. And, when four or more risk factors were present, patients were 10 times more likely to have a heart attack or stroke within two weeks after receiving IVIG. Cardiovascular risk factors include coronary artery disease, cigarette use, high blood pressure, previous stroke or arterial thrombosis, diabetes and high cholesterol. Neither the race nor the gender of the patient affected the risk of heart attack or stroke.

Since 2003, the U.S. Food and Drug Administration has required that IVIG manufacturers add a statement about the risk of stroke and heart attack to their products. The results of this study should help healthcare providers counsel patients about their risk of stroke or heart attack from IVIG treatment, as well as reduce patients' anxiety about the risks for this rare side effect. ■

Research

PIDD Studies Show Improved Diagnosis and Care

Six recent studies on primary immune deficiency disease show dramatic increases in referrals, diagnoses, treatment and testing, and compare quality-of-life issues and economic consequences for diagnosed and undiagnosed patients with PIDD. The studies, which were submitted by the Jeffrey Modell Foundation, appeared in an article titled "From Genotype to Phenotype: Further Studies Measuring the Impact of a Physician Education and Public Awareness Campaign on

Early Diagnosis and Management of Primary Immunodeficiencies" in the journal *Immunologic Research*. According to the Jeffrey Modell Foundation website, data in the studies "reflected the immunodeficiency defects of 30,283 patients globally, of which 10,192 were identified in the U.S." The data also indicated "where the patients were diagnosed and treated, who diagnosed and treated them and what type of treatment they are receiving." ■

Insurance

Stimulus to Subsidize the Cost of COBRA

With the number of layoffs at an all-time high, many people are at risk of losing their health insurance. And, while COBRA is an option, it is an expensive one. For individuals who depend on expensive IG treatments, the recently enacted federal stimulus package may help. According to *Medical News Today* (www.medicalnewstoday.com), "Under the stimulus package, workers involuntarily terminated between September 1, 2008, and December 31, 2009, whose annual incomes do not exceed \$125,000 for individuals or \$250,000 for families, qualify for subsidies to cover 65 percent of the cost of health insurance premiums under COBRA for as long as nine months."

Did You Know?

The Patient Notification System is a free, confidential, 24-hour communication system designed to provide plasma product consumers, healthcare professionals, and patient family members with timely, automatic updates about plasma product withdrawals and recalls from all participating manufacturers. To access the Patient Notification System, call 1-888-UPDATE-U (1-888-873-2838) or register online at www.patientnotificationsystem.org.

In addition, individuals with pre-existing conditions who did not take advantage of COBRA at the time of their termination are not ➤

Did You Know?

penalized by a pre-existing clause. Even if more than 63 days has elapsed (which is normally considered the period in which a pre-existing clause would take effect), individuals merely need to start paying for COBRA, and their care will be covered. However, individuals only qualify for the COBRA subsidy for up to nine months from the time they begin paying for COBRA and when the COBRA subsidy terminates on December 31, 2009. Employers were required to notify employees of the new COBRA subsidy plan no later than April 17, 2009. ■

Healthcare

Americans Cutting Back on Health Care Because of Cost

Americans are feeling the effects of the economy, and in response, are cutting back on what should be most precious to them: their health. According to the first Kaiser Health Tracking Poll of 2009, many people are postponing or skipping treatments due to cost. The Kaiser Family Foundation's Kaiser Weekly Update reported that "slightly more than half (53 percent) of Americans say their household cut back on health care." In addition, 35 percent said they are relying on home remedies and over-the-counter drugs rather than visiting a doctor, 27 percent have put off health care they need, 21 percent have not filled a prescription, and 15 percent cut pills in half or skipped doses to make their prescription last longer. For more information, go to www.kff.org/kaiserpolls/posr022509/pkg.cfm. ■

Did You Know?

Congress has appropriated funds to screen newborns for severe combined immune deficiency (SCID). The Jeffrey Modell Foundation anticipates that Massachusetts, Illinois, Connecticut, Texas and New York will move forward with pilot screening programs in 2009.

— Jeffrey Modell Foundation

Insurance

Insurers Pledge Money for Out-of-Network Rate Database

A new independent database to help determine out-of-network reimbursement rates will be funded by health insurers. The funding is part of a settlement with New York Attorney General Andrew Cuomo, who is leading an effort to reform the way insurers determine reimbursement rates for out-of-network services. Cuomo's investigation centered on a database used by many insurers to determine "usual and customary" rates, which was operated by Ingenix Inc., a subsidiary of UnitedHealthcare. Cuomo contended that "because of its parentage, Ingenix had a vested

interest in setting reimbursement rates low, allowing companies to underpay patients for out-of-network services," according to a March 10, 2009, report on Newsday.com. As part of the deal between Cuomo and UnitedHealthcare, the database operated by Ingenix will close. The new database will be funded in part from a \$50 million pledge by UnitedHealthcare, a \$10 million settlement with WellPoint Inc., parent of Anthem Blue Cross and Blue Shield of Wisconsin, as well as deals with other large insurers, including Aetna, Cigna and MVP Health Care. ■

Legislation

IVIG Access Bill Introduced

A joint effort between 18 patient advocacy and healthcare professional groups and congressional sponsors has resulted in the introduction of Senate Bill S.701, the Medicare Patient IVIG Access Act of 2009. Introduced in April, the purpose of the bill is to offer a solution to the delay in and denial of IVIG treatment due to insufficient Medicare reimbursement. Specifically, a report from the Office

of the Inspector General showed Medicare reimbursement for IVIG is lower than the cost many providers pay for the product, and as a result, a number of physicians and hospitals cannot afford to administer IVIG treatment to Medicare patients. This new bill establishes appropriate reimbursement in all sites of care for patients suffering from a multitude of diseases. ■

Research

Study Links Vitamin D to MS Susceptibility Gene

For those who suffer from multiple sclerosis (MS), new research has found evidence of a direct interaction between vitamin D and a common genetic variant termed DRB1*1501. In the study, which was published in the February 6, 2009, issue of the open-access journal *PLoS Genetics*, "researchers found that proteins activated by vitamin D in the body bind to a particular DNA sequence lying next to the DRB1*1501 variant, in effect switching the gene on." Therefore, "vitamin D deficiency may lead to lowered expression of this gene, in turn altering immune processes that ultimately trigger the immune attack on brain and spinal cord tissues in MS." The researchers caution, however, that

more studies are needed to determine whether vitamin D supplements can reduce the risk of MS. In addition, they say there is "insufficient evidence yet that vitamin D supplements can affect the course of MS once it has begun."

The American Academy of Pediatrics, however, now recommends an increase in vitamin D intake for infants and children, from 200 IU daily to 400 IU, according to a March 11,

2009, article in *The Republican* (www.masslive.com/holyokeplus/republican/index.ssf?/base/news-5/123641411052400.xml&coll=1). The article's author also states that, "Vitamin D's adequate intake is set at 200 IU for adults under age 50 and 400 IU for those over age 50. Recent research suggests those levels are much too low and recommends adults obtain 1,000 IU of vitamin D daily." ❏

Did You Know?

"Tai chi, a form of exercise and meditation, has been found to boost immunity and enhance immune function, offering benefits for patients with autoimmune disorders."

— British Journal of Sports Medicine, March 2006

Plasma Derivatives: An Overview

By Catherine Billey

Human blood plasma is used to create many products to treat rare diseases, and some new products have just been released.

Millions of Americans suffer from rare diseases or have unique medical needs for which products derived from human blood plasma play a crucial role in preserving quality of life or, indeed, in sustaining life itself.

Today, plasma derivatives are manufactured from human plasma by fractionation, a process used to isolate specific proteins needed to treat various diseases. These techniques were developed in the early 1940s by Harvard biochemist Edwin J. Cohn as a result of treating the battlefield casualties of World War II. His techniques remain the mainstay of contemporary plasma fractionation.

Approximately 55 percent of human blood is constituted of plasma, a clear, straw-colored portion of the blood that holds other cells in suspension. As the transporter for cells and numerous other substances, it is vital to human life and contains proteins for blood clotting and defending the body against infection.

What Is in Plasma?

Plasma itself is 90 percent water. Forming about 5 percent of the total human body weight, plasma comprises more than 100 different proteins, including albumin, immunoglobulins, clotting factors, fibrinogen and protease inhibitors.

Albumin, produced by the liver, is considered the most important plasma



protein because it maintains the oncotic pressure in blood vessels and has numerous transport functions. Next in significance are immunoglobulins, the plasma proteins that protect the body against infectious diseases. Clotting factors, including VIII and IX, assist in blood coagulation, together with platelets. And, finally, protease inhibitors ensure that natural reactions do not proceed uninhibited.

Where Does Source Plasma Come From?

Source plasma comes from voluntary whole blood donations at strictly

controlled plasma collection centers in the United States and Europe. However, only plasma collected in this country can be used in products that are used to treat diseases in the U.S. The process itself is called plasmapheresis, in which whole blood is separated into cellular and other components with specialized equipment in sterile, self-contained environments. This recovered plasma is then used for different medical therapies.

Only a small portion of plasma from the plasmapheresis process is used for fractionation. Most plasma comes from plasma donation centers — large

production-scale manufacturing facilities — designed to accommodate large plasma pools, which come from the combined units of thousands of carefully screened individual donations. The process used at these facilities, which returns the red cells back to the donor, allows donors to give plasma twice a week.

To ensure quality control is maintained, multiple levels of testing for infectious agents have been put into place. For example, according to the Department of Health and Human Services, nucleic acid techniques can detect tiny levels of the genetic building blocks for infectious agents such as HIV and hepatitis C. In the rare cases in which these agents are detected, the entire pool in which it was located is eliminated.

The larger, uncontaminated pools then move into the fractionation process, out of which the four finished products — albumin, immune globulins, clotting factors and protease inhibitors — are derived. The entire fractionation process takes approximately nine months from donation to medication. Therefore, if there is a high demand for these medications, that demand cannot be met overnight.

Who Manufactures Plasma Products?

The main producers of plasma-derived medicines in the U.S. include Baxter BioScience, CSL Behring, Grifols, Octapharma, ViroPharma and Talecris Biotherapeutics. Not all manufacturers make the same products from plasma. Which products they produce depends on what FDA approvals the company has been granted. All, however, must follow the same stringent FDA guidelines in sterilizing their products.

The conditions treated with plasma protein therapies include bleeding

disorders, immune system deficiencies and dysfunctions, genetic lung disorders, hepatitis, shock, trauma, burns, Rh incompatibility, cardiopulmonary needs, transplant recipients, pediatric HIV, liver conditions and rabies from animal bites.

Some Diseases Treated with Plasma-Derived Products

Hereditary angioedema (HAE) is a disease that is so rare, it often goes undiagnosed for years. Symptoms include swelling of the hands, feet, face, arms, legs and abdomen, as well as the air passages, which may cause difficulty swallowing or breathing. ViroPharma recently received approval for Cinryze, the first FDA-approved C1 inhibitor on the market for treating HAE. Other companies are in the final stages of clinical trials and approval for HAE drugs.

Not all manufacturers make the same products from plasma.

Alpha-1 antitrypsin deficiency, also known as genetic chronic obstructive pulmonary disease (COPD), is another debilitating disease treated with plasma derivatives. Patients with this disease lack a vital protein produced by the liver. In these cases, the proteinase inhibitor A1P1 is used to replace the missing protein.

Kawasaki disease (KD), an uncommon illness that typically affects toddler-age children, and is the leading cause of acquired heart disease in America's children of that age range, is treated with intravenous immune globulin (IVIG), a plasma-derived therapy. IVIG replaces essential missing antibodies in the patient's plasma. KD recently gained heightened attention when

Backstreet Boys singer Brian Littrell's young son was diagnosed with it, and IVIG was given to successfully bring down the inflammation in his coronary arteries. KD was also highlighted in the February-March 2009 edition of *IG Living*.

Congenital fibrinogen deficiency is a rare, potentially life-threatening disorder that is estimated to affect one person in every million in the United States (or 300 patients). Symptoms following an injury include excessive levels of bleeding. At birth, there is also bruising and bleeding from the umbilical cord. Diagnosis occurs when patients undergo blood coagulation testing, which determines fibrinogen levels. Recently, marketing approval was given to CSL Behring for RiaSTAP. It is the only treatment for acute bleeding episodes, and the first and only therapy for both afibrinogenemia and hypofibrinogenemia in those who have the deficiency. In a press release, Robert Lefebvre, general manager of CSL Behring, said RiaSTAP provides a new therapeutic option to support hemostasis and clot stability.

Plasma Products: A Complex Process

Products created from human blood plasma go through a lengthy, arduous process to become therapies for a number of disease states, some of them very rare. By understanding this process, patients can better appreciate the complexity of developing the life-giving products that treat their diseases, and be assured that the necessary steps have been taken to ensure the products are safe. ■

CATHERINE BILLEY is a staff writer for the *Mammoth Times* and *Sierra Magazine* in Mammoth Lakes, Calif.

Did You Know?

Reading and Understanding Your Explanation of Benefits

By Jim Trageser

Ensure that you pay close attention to the bill your insurance company sends so that you are only paying for the services you receive.



“This is not a bill” is often as far as we read when we receive a printout from our insurance carrier marked Explanation of Benefits (EOB).

But while there is an understandable relief in seeing that it’s not a bill, an EOB itself is an important document in managing our healthcare costs and lifetime benefit caps. Our EOBs from health insurance, dental insurance and prescription drug plans should be scrutinized as carefully as our credit card bills.

Verify

Mistakes happen; it’s human nature. But in a financial world that increasingly relies on lifetime health insurance caps to allow employers to manage their costs, making sure that you and your insurance carrier are billed only for the treatments and services you actually receive is more important than ever. This is particularly true for those with an ongoing medical condition, where repeat office visits create repeat opportunities

for human error to arise, and where lifetime caps are more of a concern than they are for the general population.

Every time you visit the doctor, dentist or other medical facility that is covered by your insurance plan, you will receive an EOB for that visit from your insurance carrier within a few weeks. And while specific layouts of EOB forms vary from insurance company to insurance company, all of them contain the same basic information:

- date of the visit
- doctor or medical facility you visited
- type of service you received
- amount of the bill being submitted to the insurance company
- any network savings/adjustment
- amount paid by the insurance company
- any deductible paid or owed by the patient
- balance of the bill, owed by the patient

Whenever you get an EOB, it’s important to verify that the information is accurate — that you really did go to that doctor on that date and receive the treatment listed. For instance, when I recently went to see a physician specializing in vision care for a retinal scan, my EOB entry for that visit read “Office Vision Care,” along with the date of my visit, the name of the medical group the doctor belongs to, and the amount the

doctor charged for the visit. There may also be various codes or notes inserted into a claim on an EOB, offering further information on a specific claim. (My EOB, above, included a note that routine vision exams aren't covered.)

Compare

While the EOB may list the portion of a bill that you're responsible for (either as a deduction or a non-covered procedure), you don't pay the doctor upon receiving the EOB. The care provider will also receive a version of the EOB, and will then send you a bill based on what the insurance company has paid or not paid.

When you receive the bill from the doctor or medical office, compare it with the EOB for that visit and make sure that what you're being billed matches what the EOB says you owe. If you notice a discrepancy, contact your medical provider to get an explanation. If you're not satisfied with the explanation, you need to follow up with the insurance company.

Save

Most experts advise saving your EOBs with your other important paperwork (i.e., utility bills, insurance policies, etc.) in case of disputes that may arise in the future.

Professor A. Thomas Golden at the Thomas Jefferson School of Law in San Diego, Calif., said that while most states don't treat EOBs as an implied promise or contract, laws vary widely from state to state. Golden, who teaches contract law, said insurance policies are regulated by both state contract and insurance laws, but that hanging on to your EOBs is a good idea no matter where

you live: "Should a dispute arise as to the appropriate interpretation of a vague or ambiguous term in the insurance contract, EOBs issued since the contract was entered could be used to assist in resolving the vagueness or ambiguity. This would be most helpful to the patient in situations where an insurer makes a decision in the patient's case that is less beneficial than prior decisions made by the same insurer in previously issued EOBs under the same policy."

If There's an Error

If any of the information is wrong (if, say, my EOB had read "Fertility Treatment" instead of "Office Vision Care"), then it is important to contact the insurance company immediately to get the claim corrected. Every EOB contains a contact phone number for the insurer's customer service department, and it's usually a toll-

free number. Whenever you find what you think may be an error on an EOB, you should immediately call that contact number and file an appeal.

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Understand Your Relationship

According to Golden, it is important to recognize what your relationship to your health insurer is. If you purchase your health insurance through an agent on your own, then you have a contract with the insurer — meaning that if you feel the insurer is not living up to the terms of the policy you purchased, you have the right to seek legal recourse to enforce the terms of the contract. However, if you receive your health insurance

“When you receive the bill from the doctor or medical office, compare it with the EOB for that visit and make sure that what you're being billed matches what the EOB says you owe.”

through work, then it is your employer that has a contract relationship with the health insurance company. Even here, though, Golden said employees may have some ability to force the insurance company to honor a claim that you believe should have been covered by the policy.

“The fact that the employee contributes (usually through payroll ➤

through work, then it is your employer that has a contract relationship with the health insurance company. Even here, though, Golden said employees may have some ability to force the insurance company to honor a claim that you believe should have been covered by the policy.

deductions) to the payment of premiums does not make the employee a party to the insurance contract," explains Golden. "The patient/employee is in most cases an 'intended third party beneficiary' of the contract between his/her employer and the insurance company, meaning that the patient/employee may have

Checking Online

Many insurers now allow you to view EOBs online, as well as the print version they mail to you. Depending on your insurer, you may also be able to see how much of your lifetime benefit has been used, your current-year deductible and out-of-pocket amounts, and the status of any

field, there will generally be a "network savings" field (or something similar) if you're in a PPO-style health plan. This is the discount the health insurance company has negotiated with the medical (or dental) provider. (This can also lower the amount of your deductibles or co-pays.)

Those with chronic medical conditions know how quickly medical costs can add up, even with in-network discounts, and why it's so important to verify the accuracy of your health insurance accounting each time you receive an EOB. Double-checking every charge made to your insurance plan is of particular importance following hospital stays, when multiple healthcare providers may be billing your insurance separately. When our youngest was born last summer, we received separate EOBs for mom from the attending physician, the anesthesiologist, the hospital, the hospital's on-site pharmacy and the surgeon who performed the Caesarean. Then there were the EOBs for the baby's pediatrician, plus the baby's share of the hospital room charge. Given the high dollar value on many of these charges, even a single error could have resulted in a significant dent in our lifetime caps. You can be sure we checked them all thoroughly! ■

JIM TRAGESER edits the film, religion and books sections for a daily newspaper in the San Diego, Calif., area, and has contributed to two reference books on the blues.

“Whenever you find what you think may be an error on an EOB, immediately call that contact number and file an appeal.”

standing to bring legal proceedings against the insurer for breach of its contract with the employer. But the employee has no control over the terms of that contract.”

Those who work for larger companies may find that their employer is self-insured — meaning that they pay all claims out of their own funds, often hiring a health insurance company to administer their employees' claims. In such cases, employees' ability to seek recourse over a disputed claim will depend on the nature of their employment (contract, union, at-will, salaried, etc.) and the laws of their state.

Those who get their health insurance through Medicare receive it as a benefit from the government, with federal law dictating appeals processes for disputed claims.

appeals. Check with your insurer or employer for setting up an online account.

EOBs and Lifetime Caps

In an article on lifetime caps in the February-March 2009 issue of *IG Living*, it was explained that only what the insurance companies actually pay out on your behalf counts against your lifetime cap, which is the maximum amount of your medical bills that the insurer will pay over the course of your life. In reading an EOB, the amount in the field marked "paid by health plan" (or something similar) is the only amount that counts against your lifetime cap. This will almost always differ from what the medical provider charges, and this will be indicated on your EOB. In addition to the "amount charged"

Editor's Note: Many physician offices and clinics are investing in software that will estimate instantly what the expected out-of-pocket expenses are going to be for the patient. They then require 50 percent of that expense up front before they will treat the patient. This software is being provided by insurance companies, with Cigna being the latest to provide it. What used to take up to 90 days to figure out, can now be done in a matter of minutes. It's possible that this kind of system will result in even more patients going without treatment because of out-of-pocket expenses. In addition, the increase in popularity of health savings account plans has prompted some physician offices to request payments up front. For more information, you can read a recent article published in the Washington Post, "Doctors Seek Fees at Time of Service," at <http://www.washingtonpost.com/wp-dyn/content/article/2009/03/02/AR2009030201786.html?hpid=sec-health>.

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PIDD Patients and Sinusitis

Understanding the Diagnoses and Treatments

By Jennifer Kester

To alleviate sinusitis, PIDD patients need to get to the root of its cause, as well as take some additional precautionary measures.

Sinusitis causes symptoms of acute facial and head pain. Unfortunately, a number of patients see a doctor only to find that their chronic sinusitis is a symptom of primary immune deficiency disease (PIDD) — a diagnosis that offers little solace to those suffering from chronic sinusitis pain. Though each case is different, knowledge about a patient's particular form of sinusitis can empower them, and help to alleviate the recurring bouts of sinus infection that brought them to the doctor in the first place.



What Causes Sinusitis?

A number of contributing factors are likely behind sinus trouble, but five in particular are worth bearing in mind.

Gastroesophageal reflux disease (GERD). GERD is an often-overlooked factor that can cause sinusitis. GERD arises due to acid reflux from the stomach. “Normally, the lower end of the esophagus, as it attaches to the stomach, should be ‘squeezed shut’ by the action of the diaphragm, as [acid] passes through the diaphragm,” says Dr. Terry Harville, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences. In patients with GERD, acid readily passes into the esophagus. While sitting or standing upright, the acid may not travel very high, but once lying down, it can pass into the oral pharynx. From there, it can readily get into the eustachian tube (the tube connecting the middle ear with the upper part of the pharynx near the nasal passages), especially in younger children, and result in ear infections. The acid can pool on top of the adenoids in the back of the throat and initiate inflammation and infection, which then disrupts the ability of the uvula to properly close off the nose. Then, acid can reflux into the nose and sinuses, or the inflammation and infection from the adenoids can pass into the nose and sinuses. In worse cases, the acid also can flow into the trachea, resulting in lung problems.

To deal with GERD, sometimes aggressive therapy is necessary. Aggressive therapy involves the use of high doses of antacid medications. For example, Harville says, a child taking histamine blocker ranitidine would use 8 to 10 mg per kg divided twice a day, rather than 4 mg per kg, which pushes the dose to a slightly higher level. For an adult who takes a medicine once a day, the prescription may be upped to using it twice daily, and secondary medications may be given to promote gastrointestinal motility. If aggressive therapy doesn’t help GERD, surgery may be the next step. The anti-reflux surgery is known as Nissen fundoplication or just fundoplication. “In essence, it is using the stomach to wrap up around the esophagus, creating a valve to prevent stomach contents from passing back into the esophagus,” Harville says. (See additional information about GERD in this issue’s article,

Knowledge about a patient’s particular form of sinusitis can empower them, and help to alleviate the recurring bouts of sinus infection.

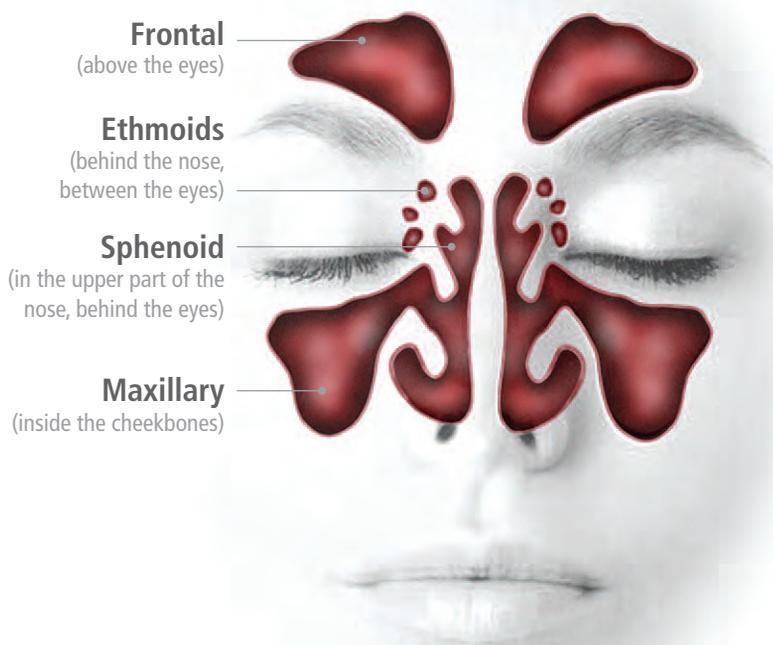
GERD and Coughing: What PIDD Patients Need to Know, on page 22.)

Structural defect. Structural defect is another condition that can result in sinusitis. Anatomic problems that prevent the drainage of fluids cause recurring infections. Typical defects include polyps, a growth on a mucous membrane; a deviated septum; abnormally small sinus passages; and enlarged turbinates, which are the thin plates on the walls of the nasal chambers. According to Dr. Alice Lee Kuntz, an otolaryngologist (more commonly known as an ENT—ear, nose and throat specialist) at Bellevue ENT Inc., Bellevue, Wash., larger structural defects such as a deviated septum, enlarged turbinates and large polyps can be detected during a visual exam. But, she says, imaging studies such as a CT scan are needed to take a closer look for narrow passageways, chronic infection, inflammation and smaller polyps.

Surgery may be required to fix structural defects, though the proper course of action will depend on the patient’s history, as well as the nature of the defect. According to Harville, the simplest option is to flush the sinuses, draining these passages while also looking out for organisms that may be causing painful inflammation. If this doesn’t work or isn’t suitable for the patient, doctors may use surgery to create better drainage in the sinus cavities.

“More aggressive forms of surgery actually result in ‘cutting’ of the tissues and possibly bone, for example, to open the sinus openings or to create new openings,” Harville says. “This latter form of surgery may be helpful in adults, but frequently results in more problems in children. We tend to recommend against this latter surgery, because in patients with immunodeficiencies, frequently the tissue never fully heals or recovers, [and] therefore, recurrent procedures are required. In children, the lack of healing is extremely important.” Other surgeries that can be useful, if needed, include the correction of a deviated septum or the removal of enlarged turbinates.

Kuntz warns that when it comes to surgery for children, doctors have to be very selective in the scope and use of incisions to avoid leaving behind surgical wounds. The most important thing for a child who has an immune deficiency, she says, is to treat the immune deficiency as aggressively ➤



as possible before jumping into surgery. Surgery is only helpful, she adds, if there's an anatomical problem, such as a deviated septum that needs correction or enlarged turbinates that may require revision.

Allergies. Allergies are also a contributing factor to sinusitis. Patients should work with their doctors to check for any allergies and figure out how to avoid or treat them. If a patient suspects allergies may be exacerbating their condition, a good rule of thumb is to avoid allergens such as pollen, pet dander, mold and dust mites. Their doctor might prescribe some medications to combat these allergies, such as antihistamines, decongestants, corticosteroids and leukotriene modifiers. However, unless patients have had prior sinus surgery, which provides a clearer passageway to sinuses, Kuntz says that nasal rinses won't treat the infection itself. But even without a previous surgery, nasal rinses are still helpful for washing irritants that are known to trigger sinus infections, such as allergens, out of nasal passages.

Trough levels. Patients who suffer from chronic sinusitis should have their doctor regularly check their trough levels, the amount of immunoglobulin (IG) in their blood right before their infusions, to see if they are at the proper IVIG (intravenous immunoglobulin) dose. After an infusion,

these levels will spike, but IG levels then steadily decrease until the patient's next infusion.

According to Harville, higher infection rates can correlate to lower trough levels. "In growing children, the dose should be adjusted often to accommodate growth, and troughs should be used again to demonstrate sufficient dosing—as long as there are no infections." However, Harville warns that checking trough values and maintaining higher levels of IG may be deceptive. Ideally, he says, trough levels should be about 1,000 mg/dL, which is a departure from the previously accepted notion that a trough greater than 400 mg/dL was adequate. "The trough should be demonstrated to indicate that [a] sufficient amount of IVIG is being given, but should not be used to demonstrate that it is 'adequate,' since some patients require trough values of 1,000 mg/dL to control sinus disease," he says. "If chronic infections are present, the dose of IVIG should be increased, and antibiotics used to control the infections, but the trough should not be used to demonstrate 'adequacy' of treatment. Indeed, if the trough is very good, the dose and dosing interval seem reasonable, and appropriate antibiotics are being used, then one should be looking for things like GERD, fungal infection in the airways, tracheal esophageal fistula, cleft palate—especially submucous cleft—ciliary dysfunction, etc."

Cilia disease. Another common cause of chronic sinusitis in PIDD patients is cilia disease or dysfunction. The cilia are microscopic hairs on the nasal membranes that act like oars to drain the mucous produced naturally by the body. Some viruses, exposure to cigarette smoke and other inflammatory processes can paralyze and even destroy cilia. When this happens, the excess mucous gets trapped in the sinuses, which leads to sinus pain and headaches.

Harville says that ciliary dysfunction is evaluated by carefully scraping cells from inside the nose and examining them under a light microscope to see whether a uniform and appropriate beat pattern—that is, the hair-like cilia sway in a repetitive cycle—is present, and then examining a specimen by electron microscopy to determine if the internal structure is normal. "Typically if there is true ciliary disease, there is the condition of situs inversus, or the internal structures of the body, including heart, lungs, liver, intestines, etc., are on the reverse side," he says. "Cilia are necessary

for the normal placement of the organs during development. Therefore, the risk for ciliary disease can be obvious in this setting. Less obvious would be ciliary dyskinesia, where they fail to beat in an appropriate uniform pattern to move mucous—this is why the light microscope exam is needed.”

If ciliary disease is the culprit, IVIG, daily antibiotics, nasal flushing, nebulized antibiotics (such as Tobi) and nebulized anti-mucolytic agents (like Pulmozyme) can all be useful, Harville says. “We may also use devices to rapidly inflate and deflate the lungs or vibrate the body, to attempt to break up mucous and help with its removal from the body with postural drainage, i.e., [putting the] head lower than [the] rest of [the] body.”

Other causes. The National Institutes of Health asserts that the above five conditions may not be the only causes of sinusitis. Other factors that will make PIDD patients susceptible to recurring sinus infections include air pollution and smoke; asthma; changes in altitude (such as flying or scuba diving); dental work; sticking a foreign body into the nose; frequent swimming or diving; hospitalization, especially if in the hospital because of a head injury or if a tube has been placed into the nose (a nasogastric tube); pregnancy; and overuse of nasal decongestants. Pay special attention to nasal decongestants. According to the National Institutes of Health, nasal decongestants may help at first, but using them beyond three to five days can actually worsen nasal congestion. Harville adds that injuries to the nose and face—whether they are from boxing, football, car accidents and so on—are also risk factors for chronic sinusitis.

How to Avoid Sinusitis?

Patients can take some measures to keep their sinuses clear of infections, but they should be sure to get approval from their doctor before trying them. Getting proper and consistent sleep; maintaining a good diet; avoiding alcohol and triggers; drinking lots of fluids; and washing hands well are all common-sense steps to take. But, patients also may want to look into using a saline nasal rinse; making use of a steroidal nose spray or a nose spray with antibiotics; using a nasal antihistamine such as Astelin; getting nasal respiratory treatments; using humidifiers to prevent sinuses from getting too dry; taking prophylactic antibiotics; employing a daily proton pump inhibitor (if affected by GERD); utilizing H2 antagonists, such as Zantac; and taking Afrin a half hour before take-off when traveling by plane.

When patients are in the throes of an infection, Harville says the following might help provide relief (of course,

Signs of a Sinus Infection

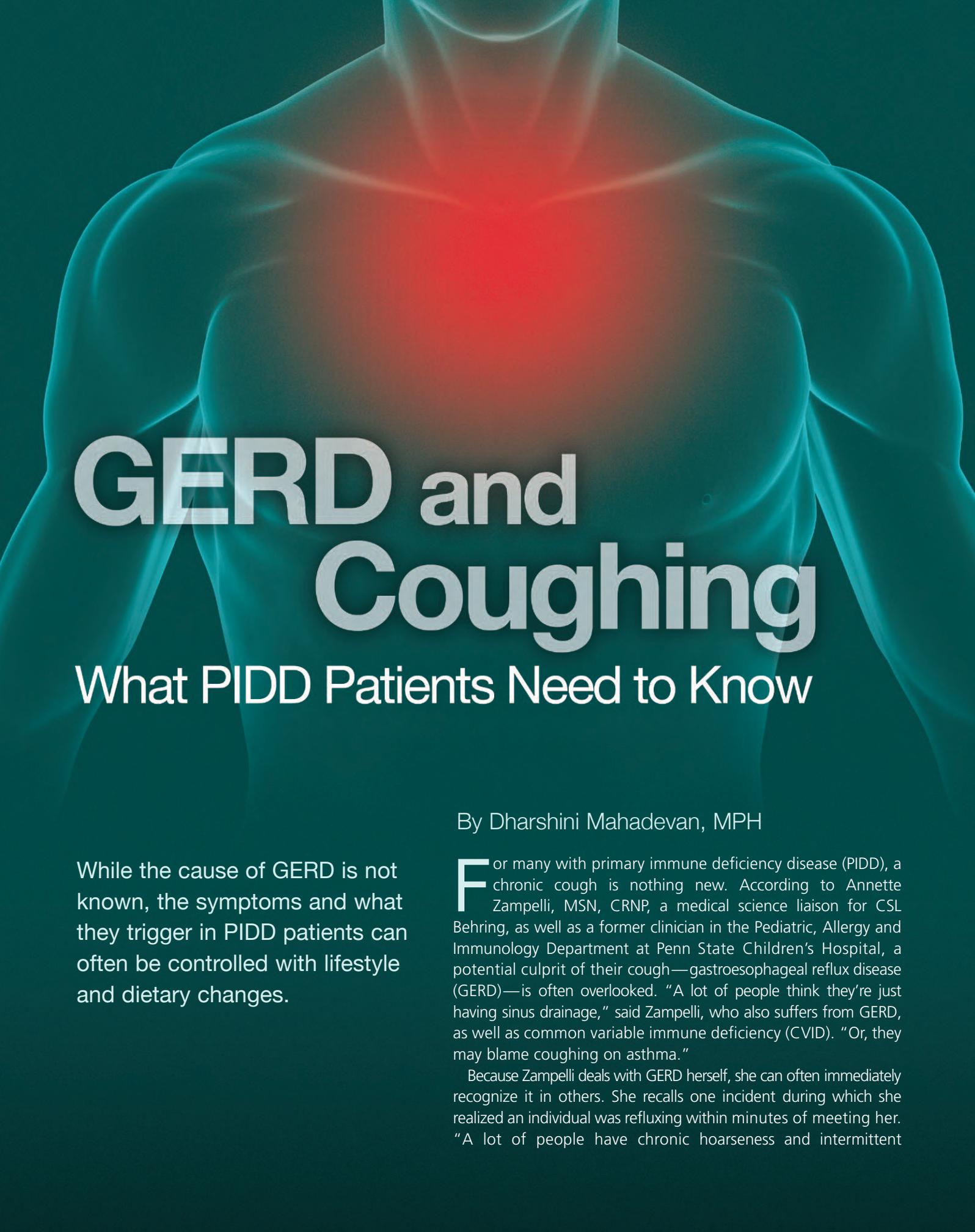
Sometimes it can be hard to tell whether sniffles are just a cold or a full-blown sinus infection. Most cases of sinusitis begin with a common cold. But those colds can inflame sinuses and cause sinusitis. Sinusitis can be acute, when it lasts two to eight weeks, or chronic, when the symptoms aggravate for much longer. According to the National Institutes of Health, these symptoms include:

- Bad breath or loss of smell. Many parents with kids who have PIDD recognize this as the first sign. The kids’ breath usually has a unique fetid odor.
- Cough. The cough is often more severe at night.
- Fatigue and general ill-feeling.
- Headache. Pressure-like pain behind the eyes or forehead, a toothache, or other facial tenderness point to sinusitis.
- Nasal congestion and discharge.
- Sore throat and postnasal drip. The postnasal drip usually consists of thick secretions that are yellow, green or spotted with blood.

patients should consult a doctor first to determine if these are appropriate for their condition): a nose spray with antibiotics; a steroidal nose spray; a nasal antihistamine nose spray; antibiotic ointment Bactroban Nasal; nebulized antibiotics; or oral antibiotics. In severe cases where bone is involved, IV antibiotics could become necessary. Kuntz says that she reserves nasal antibiotics for patients who have had sinus surgeries. As with nasal rinses, surgeries create easier passageways to the sinuses for the medicine. Without this, she says, the antibiotics will reach only the nasal passage, not sinus cavities, where the infection resides.

Ultimately, patients’ best defenses may be to have an ENT (not a primary care physician) take a culture to find out what, if any, kind of bug is growing to better diagnose the course of treatment needed. While a primary care physician can take a nose swab, that method doesn’t get at the bacteria causing the infection, explains Kuntz. ENTs, on the other hand, have special equipment to get past the turbinates and into the sinus area to get an effective culture. ■

JENNIFER KESTER is a San Diego-based writer and editor specializing in health and lifestyle issues.



GERD and Coughing

What PIDD Patients Need to Know

By Dharshini Mahadevan, MPH

While the cause of GERD is not known, the symptoms and what they trigger in PIDD patients can often be controlled with lifestyle and dietary changes.

For many with primary immune deficiency disease (PIDD), a chronic cough is nothing new. According to Annette Zampelli, MSN, CRNP, a medical science liaison for CSL Behring, as well as a former clinician in the Pediatric, Allergy and Immunology Department at Penn State Children's Hospital, a potential culprit of their cough—gastroesophageal reflux disease (GERD)—is often overlooked. “A lot of people think they're just having sinus drainage,” said Zampelli, who also suffers from GERD, as well as common variable immune deficiency (CVID). “Or, they may blame coughing on asthma.”

Because Zampelli deals with GERD herself, she can often immediately recognize it in others. She recalls one incident during which she realized an individual was refluxing within minutes of meeting her. “A lot of people have chronic hoarseness and intermittent

coughing because GERD can cause a laryngeal spasm," explains Zampelli. "It also causes inflammation of the vocal cords, which causes them to spasm and leads to irritation to the surrounding tissues."

To determine whether GERD is a factor in one's cough, Zampelli recommends that patients pay attention to whether they wake up with morning hoarseness, if they seem to cough more after they lie down or if certain foods make their symptoms worse. In addition, Zampelli suggests that patients track symptoms by using "a food diary to see if there's any correlation with certain things. If they see there's a pattern, it's something they should look at with their doctor."

What Is GERD?

Commonly referred to as acid reflux, GERD occurs when stomach contents regularly return up into the esophagus. This recurrence takes place where the stomach and esophagus meet, at the lower esophageal sphincter (LES). After one swallows, the LES muscle relaxes to allow food to pass through the esophagus into the stomach. It then contracts to prevent food and acid from coming up to the esophagus. However, when the LES is weakened, it results in backward flow of stomach acids into the esophagus, leading to stricture and scarring of the esophagus.

What Causes GERD?

While the exact cause of GERD remains unknown, many believe hiatal hernias are a main cause. Hiatal hernias occur when a part of the stomach slips through the diaphragm into the chest cavity. The role of the diaphragm is to separate the stomach from the chest and assist the LES in keeping things in the stomach. But, when a hiatal hernia occurs, the diaphragm can no longer help the LES, often resulting in backward flow of stomach contents. Other causes of GERD include obesity and pregnancy—which have been known to cause hiatal hernias—as well as unhealthy diet and lifestyle. For instance, smoking and certain foods may weaken the LES.

For PIDD patients, the LES can weaken from coughing due to sinopulmonary problems. And, depending on the individual, GERD can be caused by a varying amount of reflux. Esophageal damage is more common when the reflux is very acidic and occurs frequently, and when there is slow clearing of acid by the esophagus.

What Are the Symptoms of GERD?

The most common symptoms associated with GERD are frequent heartburn (two to three times per week) and acid

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regurgitation. Some people have GERD without heartburn but may experience chest pain, difficulty swallowing or hoarseness first thing in the morning. In more severe cases, GERD may result in vomiting and bleeding. Other symptoms include chronic cough, new-onset asthma, acidic taste in the throat, odynophagia (painful swallow), persistent sore throat, feeling of a lump in the throat and upper abdominal pain.



GERD and Asthma

GERD is a possible trigger for asthma, and GERD symptoms tend to be more common in patients with asthma versus those in control populations. Respiratory symptoms are increased in patients with GERD, and an estimated 75 percent of patients with asthma suffer from GERD. The association between GERD and asthma seems to strengthen with severity of either condition. Patients with severe asthma who do not respond to treatment may have worsening GERD. Reciprocally, patients who have severe GERD and who do not respond to treatment may have worsening ➤

asthma. Common factors that link GERD to asthma are a non-allergic component, nocturnal cough and exacerbation of asthma after heartburn or regurgitation.

GERD can affect asthma when acid from the stomach is refluxed and aspirated into the lungs and airway. When this occurs, breathing becomes more difficult and results in coughing, and if the airway is narrowed, shortness of breath may result.

Asthma may also be triggered by patients with GERD who do not display symptoms. In these cases, esophageal pH monitoring or an empiric three-month trial of vigorous acid suppression is often recommended.¹

Some potential factors that may cause GERD in asthma patients include autonomic dysregulation, increased pressure gradient between the thorax and abdominal cavity and

asthma medications. Some medications such as theophylline (also known as dimethylxanthine and used to treat asthma or COPD), beta-agonists and corticosteroids may worsen GERD.

There has been discussion that dysregulation and dysfunction of the innervating nerves of the esophagus may cause burning in the sternal area, as well as relaxation of the LES. In addition, dysregulation and dysfunction of the nerves that innervate the airways may directly or indirectly trigger symptoms of asthma, such as cough and chest tightness.² This suggests that the nervous system may act as a link between GERD and asthma.

GERD and Pulmonary Function

The association between GERD and pulmonary disease may be due to microaspiration of gastric contents and vagal

Suggested Foods for Patients Suffering from GERD

Food group	Foods usually well tolerated	Foods that may cause distress
Milk products	Fat-free or low-fat milk; low-fat buttermilk; fat-free or low-fat yogurt	Whole milk; chocolate-flavored milk products
Breads and grains	Plain bread; whole grain flour; waffles; muffins with low-fat ingredients; bagels	Breads/grains/cereals with high fat ingredients (i.e., croissants, donuts, granola)
Fruits	Fresh, frozen or canned fruits that have no citrus; non-citrus juices	Citrus juices, such as pineapple, grapefruit, orange, lemon, tangerine
Vegetables	Fresh, frozen or canned vegetables without added fat	Creamy vegetables; fried vegetables; tomatoes and tomato pastes and sauces; any tomato products
Soups	Fat-free broths; soups with lean meat; vegetable soup	Tomato-based soup; creamy, high-fat soup with high-fat meat
Dessert	Low-fat desserts; low-fat ice cream; low-fat custards and puddings; Jell-O™	High-fat desserts such as cookies, pastries, cakes and pies; chocolate-flavored desserts
Sweets	Honey; jelly; syrups; hard candy	Chocolate, cream-stuffed candies or chocolates
Meat, poultry, meat substitutes and other proteins	Chicken without skin; lean meat; fish; lean pork; shrimp; lobster; crab; tofu; low-fat lunch meat; low-fat hot dogs; eggs	Fried chicken, meat, fish and eggs; high-fat lunch meat; high-fat sausage
Condiments, etc.	Garlic; non-caffeinated tea; salt; herbs and spices as tolerated	Peppermint; coffee; caffeinated tea; liquor and wine; mint-flavored candy and gum; carbonated beverages; jalapeno peppers; chili sauce or chili pepper
Other starches	Baked potato; mashed potatoes; sweet potatoes; fat-free refried beans; pasta with low-fat cream sauce; rice	French fries; refried beans; potato chips; pasta with high-fat cream sauce; pasta with tomato sauce

nerve-induced bronchospasm from gastric acid irritation of the esophagus. Therefore, certain pulmonary diseases associated with GERD may include pulmonary fibrosis, pneumonia, chronic bronchitis and, as mentioned above, asthma.³ This connection suggests that GERD may be a risk factor for exacerbation of COPD (chronic obstructive pulmonary disease). According to a study by Rascon-Aguilar et al., patients who have COPD and reflux symptoms at least once a week have a higher likelihood of increased COPD exacerbations versus COPD patients who present with no symptoms or have GERD less than once a week.³

Patients who experience acid reflux into the throat over and over again may develop inflammation of the vocal cords, a hoarse voice or a sore throat. If acid gets inhaled into the lungs, this may result in aspiration pneumonia. In more severe cases, when reflux is chronic, pulmonary fibrosis may even occur.

Long-Term Complications of GERD

In fact, the majority of patients with GERD do not develop serious complications, especially if treated appropriately. However, certain complications may develop in those with more serious GERD. In addition to the above mentioned pulmonary diseases, other potential complications include the following:

- *Barrett's esophagus*: This complication occurs when there is repeated damage to the esophageal lining, resulting in the replacement of squamous cells (which normally line the esophagus) with intestinal cells. These intestinal cells pose a small risk of becoming cancer cells, causing esophageal cancer. Therefore, in the small population of GERD patients who do develop Barrett's esophagus, periodic endoscopies are recommended.
- *Ulcers*: Formation of esophageal ulcers may occur due to burning from stomach acid, and may even cause bleeding.
- *Esophageal stricture*: Scarring and narrowing of the esophagus can occur from acid damage. Narrowing is caused by the development of scar tissue formed as a result of ulcers. This narrowing may create a blockage, which can cause food to get stuck in the esophagus.

Treatment of GERD

Certain lifestyle and dietary changes may assist in the treatment of GERD. However, in more severe cases, these modifications alone will not treat GERD. Patients should consult with a physician regarding medication options appropriate for them.

Lifestyle changes that can aid in the management of GERD include:

- Eat smaller meals; avoid large portions.
- Wear loose-fitting clothes and belts.
- Maintain a healthy weight to help decrease intra-abdominal pressure caused by extra weight.
- Quit smoking.
- Avoid bedtime snacks and late-night eating; eat three to four hours before lying down.
- Elevate the head of your bed by six inches to decrease the chance of regurgitation of stomach contents back up into the esophagus.
- Consider over-the-counter antacids for immediate relief of symptoms.
- Avoid alcohol, and limit caffeine intake.

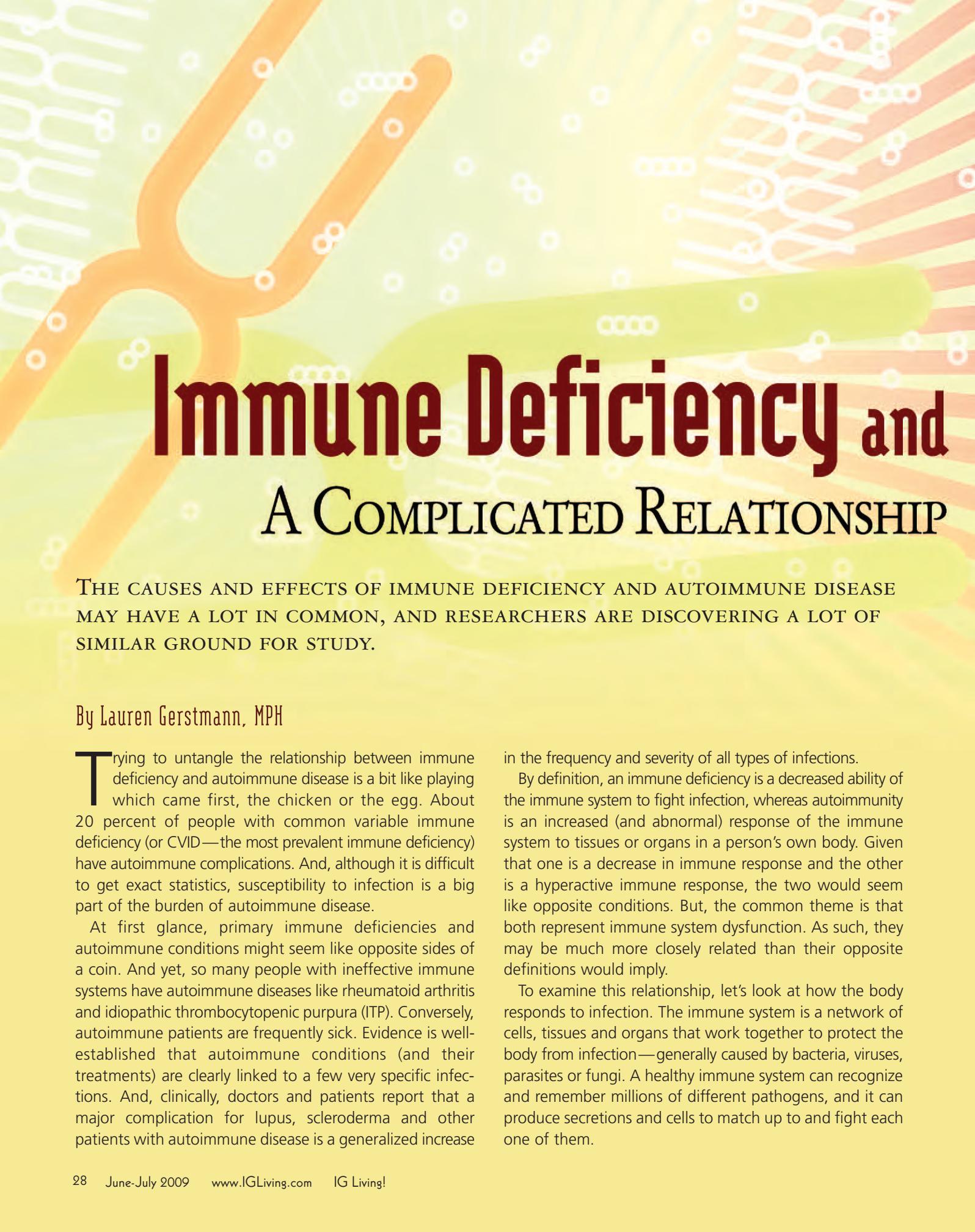
Patients should understand that they do not need to completely eliminate food they truly enjoy. They should pay attention to which specific foods exacerbate symptoms, and then decrease intake of those foods. Nutritional management of most conditions, including GERD, varies from person to person. Therefore, each patient will need to find out what helps in alleviating his or her individual symptoms. The goal is to minimize reflux of gastric contents and to identify foods that irritate the esophagus. ■

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*GERD can affect asthma
when acid from the
stomach is refluxed
and aspirated into the
lungs and airway.*



Immune Deficiency and A COMPLICATED RELATIONSHIP

THE CAUSES AND EFFECTS OF IMMUNE DEFICIENCY AND AUTOIMMUNE DISEASE MAY HAVE A LOT IN COMMON, AND RESEARCHERS ARE DISCOVERING A LOT OF SIMILAR GROUND FOR STUDY.

By Lauren Gerstmann, MPH

Trying to untangle the relationship between immune deficiency and autoimmune disease is a bit like playing which came first, the chicken or the egg. About 20 percent of people with common variable immune deficiency (or CVID—the most prevalent immune deficiency) have autoimmune complications. And, although it is difficult to get exact statistics, susceptibility to infection is a big part of the burden of autoimmune disease.

At first glance, primary immune deficiencies and autoimmune conditions might seem like opposite sides of a coin. And yet, so many people with ineffective immune systems have autoimmune diseases like rheumatoid arthritis and idiopathic thrombocytopenic purpura (ITP). Conversely, autoimmune patients are frequently sick. Evidence is well-established that autoimmune conditions (and their treatments) are clearly linked to a few very specific infections. And, clinically, doctors and patients report that a major complication for lupus, scleroderma and other patients with autoimmune disease is a generalized increase

in the frequency and severity of all types of infections.

By definition, an immune deficiency is a decreased ability of the immune system to fight infection, whereas autoimmunity is an increased (and abnormal) response of the immune system to tissues or organs in a person's own body. Given that one is a decrease in immune response and the other is a hyperactive immune response, the two would seem like opposite conditions. But, the common theme is that both represent immune system dysfunction. As such, they may be much more closely related than their opposite definitions would imply.

To examine this relationship, let's look at how the body responds to infection. The immune system is a network of cells, tissues and organs that work together to protect the body from infection—generally caused by bacteria, viruses, parasites or fungi. A healthy immune system can recognize and remember millions of different pathogens, and it can produce secretions and cells to match up to and fight each one of them.

HOW THE IMMUNE SYSTEM WORKS

All blood cells, including the white blood cells destined to become immune cells, originate in the bone marrow and then grow into specific immune cell types, such as T cells and B cells (the main types of lymphocytes), and phagocytes. The immune system stockpiles a huge arsenal of cells. Some immune cells (like T cells) take on all comers, while others (like B cells) are trained on highly specific targets.

to the redness, warmth, swelling, pain and loss of function that characterize an inflammatory response.

To work effectively, most immune cells need the cooperation of their comrades. The immune system stores just a few of each kind of the different cells needed to recognize millions of possible enemies. When an antigen appears, those few matching cells multiply into a full-scale army. After their job is done, they fade away, leaving sentries behind to watch for future attacks.¹

Autoimmune Disease

T cells contribute to immune defenses in two major ways: Some (helper T cells) direct and regulate immune responses; others (killer and natural killer—NK—T cells) directly attack infected or cancerous cells and “kill” them by releasing toxic chemicals.

Each B cell is programmed to make one specific antibody that targets an invader cell for destruction. For example, one B cell will make an antibody that blocks a virus that causes the common cold, while another produces an antibody that attacks bacteria that cause pneumonia.

Antibodies are types of immunoglobulins. Different types play different roles in the immune defense strategy:

- Immunoglobulin G, or IgG, works to coat microbes, speeding their uptake by other cells in the immune system. There are four subclasses of IgG.²
- IgM is the first antibody to be made in response to an infection, and it causes other immune cells to destroy foreign substances.³
- IgA concentrates in body fluids—tears, saliva, the secretions of the respiratory tract and the digestive tract guarding the entrances to the body.
- IgE, whose natural job probably is to protect against parasitic infections, is also responsible for the symptoms of allergy.
- IgD remains attached to B cells, and plays a key role in initiating early B-cell response.

Roughly 25 “complement” proteins aid antibodies in destroying bacteria. Complement proteins, which cause blood vessels to become dilated and then leaky, contribute

Clearly, the immune system is a very complex system with many interdependent parts. Because of this complexity, it is easy for part of the system to break down or misfire—causing anything from a simple isolated illness, to a chronic allergy, to a significant immune deficiency that impairs quality of life. For example, more than 50 percent of primary immune deficiency cases involve some sort of failure in antibody production, resulting from a complete absence of B cells (and a resulting complete absence of immunoglobulins) or by a defect anywhere along the line of production that might simply result in an IgG subclass deficiency. The severity of the immune deficiency depends on how much of the immune system remains intact.⁴ One of the most severe presentations is SCID, or severe combined immune deficiency, which involves a major defect in T cell production and function, with contributing defects in B-lymphocytes, and in some genetic types, in NK cell production as well.⁵ Unlike some less comprehensive immune deficiencies, which can be treated with antibiotic therapy or with IVIG, SCID can be treated only by a bone marrow transplant, which is effectively an immune system transplant.

A misfire in the system can cause the immune system to wreak havoc in the form of cancer or autoimmune disease. In autoimmunity, B cells develop antibodies to your own organs and/or tissues, misidentifying parts of the body as foreign invaders. Autoimmune conditions are surprisingly common, as conditions like diabetes or thyroid disease may have autoimmune causes.⁶ Lupus, a systemic autoimmune disease affecting more than 1.5 million to 2 million ➤

Americans, causes inflammation and other damage in one or more organs or organ systems and can distress everything from the skin and joints to the lungs, kidneys, blood, brain or other organs and tissues. Untreated, lupus can have fatal consequences for the kidney, heart and brain.⁷

WHAT IS THE CONNECTION BETWEEN IMMUNE DEFICIENCY AND AUTOIMMUNE DISEASE?

According to Dr. Josiah Wedgwood, chief of the division of Allergy Immunology and Transplantation at the National Institute of Allergy and Infectious Diseases (part of the National Institutes of Health), “there appears to be [quite a bit] of dysregulation of the immune system in people with autoimmune disease,” and clinicians who treat patients with autoimmune disease and immunodeficiency are beginning to notice a similarity in symptoms. In other words, “people with autoimmune diseases have the same problems that people with immunodeficiencies have.” Researchers are beginning to realize that there are a few key genes that are significant in both immunodeficiency and autoimmunity. According to Wedgwood, “Peter [Gregersen]⁸ and others have been investigating the genes that are involved in autoimmune disease. Well, guess what? The genes that they are identifying are the same genes that the people in the primary immunodeficiency field are identifying as the source of primary immunodeficiency!”

Given that many medications used to treat autoimmunity broadly suppress the immune system, it is very difficult to determine whether patients are getting infections because of the disease or because of the cure.

Sometimes, the relationship between the immunodeficiency and autoimmunity is very subtle. Researchers are learning that even though many aspects of the immune system appear to have duplicate functions, in reality, they have a protective effect that is difficult to tease out. As Wedgwood puts it, “If your T cells are working well, and your antibody response isn’t so good, you’re probably OK” —or at least you seem to be OK when you are fighting a routine infection. “But, under the same circumstances, it may be that because your antibody response isn’t so good, if you are exposed to a similar thing, you may develop an

antibody that you really don’t want to have: autoimmune disease. You survived the infection, but you get an autoimmune disease.” One of the main culprits here may well be Epstein-Barr virus, the same virus that can cause mononucleosis. In susceptible individuals, it may play a role in the development of many different autoimmune diseases, including rheumatoid arthritis and lupus.⁹

Immune deficiencies offer researchers a unique opportunity to study the function of the immune system. We know that there are a handful of immunodeficiencies (polyendocrinopathy, enteropathy, X-linked syndrome (IPEX), Omenn syndrome, autoimmune polyendocrinopathy-candidiasis-ectodermal dystrophy (APECED), autoimmune lymphoproliferative syndrome (ALPS) and C1q deficiency) that are very tightly linked with very specific autoimmune conditions.¹⁰ The reason that this is helpful is due to a concept called “penetrance.” Penetrance is another way of explaining your risk of getting a condition if you have the genes that are responsible for that condition. The immune deficiencies listed above have a very high penetrance; individuals are almost 100 percent sure to have one of these conditions if they have the genetic defect responsible. But most autoimmune deficiencies have a much lower penetrance, which can make it really difficult for researchers to find the genes responsible for them. In these specific immunodeficiencies, we already know quite a bit about the responsible genes. And, because we know a great deal about the genetic defects responsible for these conditions (and their autoimmune consequences), they can give us a lot of insight into what is causing other kinds of autoimmune conditions.

WHY DO PEOPLE WITH IMMUNE DEFICIENCY OFTEN HAVE AUTOIMMUNE COMPLICATIONS?

A working immune system is filled with redundancies; often multiple players have the same or similar function. For that reason, many members of the general population might have, for example, an IgA deficiency with no clinical symptoms. The immune system is also filled with a series of checkpoints (checks and balances, if you will) to make sure that the immune cells being produced are healthy and functional. It turns out that something like three-quarters of newly formed B cells are autoreactive,¹¹ which is just a way of saying that a majority of brand-new B cells are destined to attack the organs of the body rather than infectious invaders. But, at various points in their development, these autoreactive cells are destroyed. Failure at any of these checkpoints can cause autoimmunity. One reason people with immune deficiencies might have more

autoimmune issues may be that, in addition to generalized B cell dysfunction, they may also have defective elimination of autoimmune B cells.¹²

Interestingly, IgA deficiency, one of the more common immune deficiencies, is associated with a variety of autoimmune conditions, including rheumatoid arthritis, systemic lupus erythematosus, pernicious anemia and ITP. Even when they don't have symptoms, blood samples from patients with IgA deficiency often reveal autoantibodies.¹³ However, we don't yet know if IgA deficiency in fact causes the autoimmunity, or if it is something that simply commonly coexists with autoimmunity. The association might be explained by the fact that when individuals with IgA deficiency get certain infections, they are later more likely to develop autoimmune consequences. But, research has not yet demonstrated this conclusively.

WHAT IS THE RELATIONSHIP BETWEEN AUTOIMMUNE DISEASE AND INFECTION?

While it may seem obvious that a missing piece of your immune system weakens your ability to fight infection, the relationship between autoimmune disease and infection is more complicated. There is evidence that some infections may cause or set off an autoimmune disease. There also is evidence that autoimmune disease may make patients vulnerable to infection either because the disease wreaks havoc with the patient's immune system or because drugs taken to treat the disease (like steroids) can weaken the immune system. In addition, there is evidence that autoimmune disease may protect the patient from infection. And, there have even been a few case studies where it seems as though an infection has sent an autoimmune disease into remission!

Given that many medications used to treat autoimmunity broadly suppress the immune system, it is very difficult to determine whether patients are getting infections because of the disease or because of the cure. And, there are some very disturbing reports of specific illnesses that can be directly linked to immunosuppressive drugs. For example, one of the known side effects of certain drugs that target tumor necrosis factor (or anti-TNF drugs) is that in rare cases, patients become susceptible to progressive leukodystrophy (PML), which is fatal. And, now, we are learning that there are other immunosuppressive drugs that might carry this risk. According to Wedgwood, "there are now reports associated with Rituximab in the treatment of a number of autoimmune diseases and again very recently with the use of a drug called Efalizumab in the treatment of psoriasis." As he explains, PML "is the result of the presence of an

unchecked virus that is present in the brain of a large number of us, probably including you and me. With a normal immune system or a relatively normal immune system, you manage to control the virus. But, when you are treated with these agents that blunt your immune system, you lack the ability to control the infection and you get these horrible sequelae. It doesn't happen to most people, [but] it can happen to a few, and obviously it can be devastating."

A working immune system is filled with redundancies; often multiple players have the same or similar function.

In fact, many physicians and researchers believe that it is not merely these treatments that make autoimmune patients more susceptible to infection. And, according to Wedgwood, reports dating back to the 1950s (prior to modern treatment protocols) show that patients with autoimmune conditions were suffering a disproportionate number of infections before they began treatment. With modern treatment protocols, however, we do not find untreated patients in the literature. And so, it becomes very difficult to ascertain the role of autoimmunity itself on susceptibility to infection.

One of the recent breakthroughs in our understanding of autoimmunity comes from a new study by Isnardi,¹⁴ who according to Wedgwood, has discovered that "there is a control point in the development of autoantibodies produced in the cell that is defective in a number of individuals with primary immunodeficiencies, and that probably that defect ... is present in people with autoimmune disease."

WHAT ROLE DOES IVIG PLAY IN IMMUNE SYSTEM DYSFUNCTION?

Immune globulin therapy (IVIG) is used to support the immune systems of people with immune deficiencies, but also to regulate the immune systems of people with certain kinds of blood cancers (like leukemia and lymphoma) and people with autoimmune conditions.¹⁵ In immune deficiency, IVIG can be a replacement for what the body is missing. In autoimmune or inflammatory disease, IVIG serves more of a regulatory function, interacting with various parts of the immune system to help them work more appropriately. Interestingly, the dosing is very different in these conditions.¹⁶ People with primary immune deficiencies need a much ➤

smaller dose of IVIG to manage their symptoms than do people who are using IVIG to manage an inflammatory or autoimmune condition.

Research regarding how this might impact someone who has both an immune deficiency and a significant autoimmune condition is limited to case reports (there aren't any big clinical studies). But, the case reports do indicate that a regular replacement dose of IVIG can help control autoimmune arthritis.¹⁷ A mother whose daughter has both CVID and rheumatoid arthritis, and who receives dosing at the immunodeficiency level, says that level of dosing seems to help manage her daughter's arthritis symptoms. It doesn't get rid of the pain, but it makes it manageable. When her daughter gets sick, her pain intensifies. When IVIG controls her infections, it helps prevent her pain flare-ups. But, even on a day-to-day level, IVIG blunts the pain a bit. When the daughter was on SCIG (subcutaneous immunoglobulin therapy, which kept the amount in her system more constant), her pain was still there, but it was better controlled.

CONCLUSIONS

This overview of the current thinking on the relationship between immune deficiency and autoimmunity, and what that relationship means for vulnerability to infection, is really broad. Research in this area is often condition-specific, even gene-specific. Frequently, the research is sharply separated by field—with immunology researchers being distinct from rheumatology researchers—which can make it hard to synthesize the latest knowledge.

Further complicating the picture is that the terms “immune deficiency” and “autoimmune condition” are extreme

generalizations. The World Health Organization has identified more than 80 kinds of primary immune deficiency diseases,^{18,19} each of which affects the body in different ways. And, there are also more than 80 known autoimmune diseases.²⁰ Many people have autoimmune indicators without having a diagnosed condition; we do not know the implications for the health of their immune system or how this might affect their immune system response. Also, an autoimmune condition that targets a very specific organ (for example, localized scleroderma that causes hardening of a small patch of skin) might have a different impact on immune function from a systemic disease (for example, the diffuse form of scleroderma that may affect the entire skin, as well as the lungs, gastrointestinal tract and many other organs).

But, what we do know is that knowledge in this area is evolving rapidly. And, as it evolves, it is becoming increasingly clear that immune deficiency and autoimmunity are not so distinct after all. They are both caused by immune dysfunction. And, one dysfunctional gene can be responsible for both a deficiency and an autoimmune response. Rather than being opposite sides of the coin, or different ends of the spectrum, immune deficiency and autoimmunity may simply be different expressions of a related dysfunction. ■

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Ask Kris

By Kris McFalls

Ellen | As someone who has selective immunodeficiency and receives regular infusions of IG, I am wondering how this deficit specifically affects the digestive system. My understanding is that this disease affects the mucous membranes of the respiratory and digestive systems. I have found information about the respiratory system, but I haven't found information about how the disease adversely affects the digestive system. What are some of the symptoms, challenges and ways to cope with this organ system? It is difficult to know what is caused by my chronic illness versus what is caused by something new and/or different.

Kris | This is a common issue among the immune-deficient population. I asked Dr. Terry Harville to address it for you.

Dr. Harville | This is a very important issue. In brief, the questioner asks how antibody deficiencies affect the gastrointestinal (GI) tract. The answer is somewhat complex. First, the GI tract is, by some accounts, the largest "immune organ" in the body. Throughout the GI tract, there are aggregates of lymphocytes—many of which are collected into areas known as Peyer's patches. As it turns out, the GI tract has tremendous exposure to the "outside" world, which includes organisms that are not harmful to us, as well as those that are. The GI tract is highly populated with bacteria, most of which are important for the maintenance of our good health.

For example, there are bacteria that produce vitamin K, which we need in order to clot blood and prevent hemorrhage. Without the bacteria present, we would develop spontaneous bleeding.

For most of the development of human beings through time, food was consumed raw (i.e., not cleaned or cooked). That food, therefore, contained bacteria and parasites. An immune system needs to be active and discriminate between harmful and non-harmful organisms. As such, much immunity is located along the GI tract to carry out this function. Further, a "normally" functioning immunity prevents organisms, which would otherwise not be pathogenic, from invading into the tissues. That is, it helps to maintain a proper balance in the intestines, allowing "so-called" good bacteria to remain present, but prevents them from creating a problem by "accidentally" invading into the tissues.

When an immune system fails to work properly, this normal balance at the interface between the "outside" world and our "inner body" becomes disrupted. In this case, otherwise harmless bacteria may try to invade into the tissues. Further, pathogenic organisms may have an easier time invading into the tissues, which then results in activation of the remaining immunity in the GI tract. This results in more localized inflammation, which in turn injures the tissues more and allows further invasion of organisms, and results in more immune activation, more inflammation, etc. The physical

results of this will be symptoms such as loose stools, diarrhea, gas, cramping, etc. This chronic activation may also promote the development of autoimmune disease, such as inflammatory bowel disease or celiac disease.

Therefore, in brief, "normal" immunity allows maintenance of integrity of the interface between the outside world and the inner body at the intestines. Immunodeficiency breaks down this integrity, and results in excessive activation of immunity and inflammation in the intestines to try to control the possible invasion of pathogenic organisms, but also to try to maintain control of the organisms that are normally present. This excessive inflammation results in symptoms, and chronic inflammation can promote the development of autoimmune intestinal disease.

Unfortunately, due to the underlying immunodeficiency, patients with CVID, antibody deficiency, XLA, etc., remain at great risk for developing GI disease. ■

Terry Harville, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences.



KRIS MCFALLS has two adult sons with chronic diseases treated with IG.

Formerly a physical therapist assistant, Kris is IG Living's full-time patient advocate, and she 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.

Let's Talk!

By Shirley German Vulpe, EdD

If your life depends on immune globulin, this column is for you! Here, we have an opportunity to network and share our experiences about all of the ramifications of our illnesses, and to learn from one another.

If you have a question, comment or experience to share for a future column, email it to us at editor@IGLiving.com.

Martha Thompson is 46 years old and has three autoimmune diseases: common variable immune deficiency (CVID), bullous pemphigoid (BP) and collagenous colitis (CC). CVID is a disorder characterized by low levels of serum immunoglobulins (antibodies) and an increased susceptibility to infections. BP is a skin disease characterized by tense blistering eruptions on the surface of the skin and/or mucous membranes. CC is an inflammation of the bowel causing chronic watery, non-bloody diarrhea.

Shirley | When were you diagnosed, and what happened during the diagnostic process?

Martha | As a child, I was frequently sick with pneumonia and other infections, but in my adolescence, I was healthy. Then, at 22, I developed blisters on my face and blood blisters in my esophagus. I was very embarrassed, and I did not go to a doctor until my early 30s when the blisters spread to my mucous membranes, mouth, throat and genitalia. I was referred from doctor to doctor because no one knew what I had. Four years later, I was referred to a



Martha Thompson suffers from three autoimmune diseases and relies on IVIG for treatment.

dermatologist at the University of Southern California who performed a biopsy. He diagnosed me with BP, and depending on the amount of blisters I developed, I was taken on and off of steroids.

At 36, I was hospitalized with malnutrition. I had bad diarrhea and did not want to eat, so I was put on an intravenous feeding program called Total Parenteral Nutrition (TPN), which bypasses the digestive tract and goes straight into the subclavian vein. Despite

multiple tests, anti-diarrhea medicine and antibiotics, I continued to have problems with diarrhea and malnutrition for seven to eight years, yet no one could diagnose my problem. Finally, a doctor referred me to a specialist at the University of California, Los Angeles, who performed multiple tests, including a biopsy of my colon, and diagnosed me with CC. The specialist then referred me to an immunologist who, after performing several blood tests, diagnosed me

with CVID and started me on IVIG. In addition to IVIG, I take prednisone for BP and tincture of opium for CC, and I have continued the TPN feeding program. I also take anti-fungal medication because when I was diagnosed with CVID, I developed a very bad fungus infection in my lung, which damaged the tissue so badly, it was necessary to have the left lung removed.

Shirley | Have you had any problems receiving or paying for IVIG?

Martha | No. I have been very fortunate with my insurance. All medical care and medications have always been covered 100 percent after reaching my co-insurance payments. And, since I was not able to continue to work, I went on Social Security Disability Insurance, and was covered by Medicare, as well as my husband's insurance.

Shirley | Has IVIG helped?

Martha | Yes. I go to an infusion center and they use my TPN port for my IVIG. I have had a decrease in infections, and because of the medications, the yeast infections and blisters are better. I continue to have problems with malnutrition. But, I am now well enough to work part time.

Shirley | Have you received any support?

Martha | Yes, a lot. My husband, who married me when I was healthy 15 years ago, gets frustrated and

Resources

1. Common variable immune deficiency, www.immunedisease.com
2. Bullous pemphigoid - www.medicinenet.com
3. Collagenous colitis, National Digestive Diseases Clearinghouse, www.digestive.niddk.nih.gov, (800) 891-5389.
4. Total Parenteral Nutrition, www.merck.com

scared, but he's a real trooper and extremely supportive. My mother offers to help me whenever I need her, my employers are very understanding and supportive when I am not well, my co-workers are an inspiration, and I have 14 pets that are very comforting. *IG Living* is one of the few publications that publishes articles about others with conditions similar to mine, and I find it very helpful. And, I have a lot of confidence in my physicians.

Shirley | What was the worst advice you were ever given?

Martha | Prior to my proper diagnoses, I saw a doctor who dismissed my plethora of problems as something that would pass.

Shirley | What was the best advice?

Martha | A couple of things. First, learn to listen to your body: Rest when you are tired, eat when you're hungry and don't push yourself. Second, if you encounter a doctor who seems to take no interest in your puzzling symptoms, keep looking until you find a doctor who is willing

to help you find the answers. I was lucky the day a perplexed doctor admitted he needed help and referred me to a specialist.

Shirley | Do you have any final message for those who read this column?

Martha | Yes. Don't give up. Speak up for yourself, and advocate for yourself. You can get the right help and correct treatment. ■



SHIRLEY VULPE has a doctorate degree in educational administration, a master's in early childhood special education, a BSc in occupational therapy and a diploma in physical and occupational therapy. She worked for 38 years specializing in setting up rehabilitation and early childhood special education programs. Shirley is now retired due to two autoimmune diseases: common variable immune deficiency and chronic inflammatory demyelinating polyneuropathy. She has been married for 45 years to a physician, is the mother of two children and the step-mother of five.

I Am the Coupon Queen

By Cheryl L. Haggard



Illustration by Ben Drolet

I AM A third-generation coupon queen. In this cash-strapped economy, couponing is a must! If it's in my grocery cart, shopping bag or hand-basket, it will be purchased with a small document I lovingly clipped from the Sunday newspaper and painstakingly filed in my cotton candy-pink coupon caddy. My caddy

is a holy grail of a sort: No hands are to touch it other than the second generation Queen Marion the Second, as she knows where every fragile square of discount newsprint is to be filed. Queen Mother Mary the First (may she rest in peace) routinely reminded me to "never walk away from coinage" found in the street,

as a "penny kept was a penny earned." And yes, the fourth generation is currently under my tutelage. When my 7-year-old daughter, Princess Molly, clipped her first coupon, I gently wiped a tear of pride from my cheek.

And, because my husband, Mark, and I are raising three children, two

of whom receive immune globulin for their immune deficiency, my multigenerational coupon habit has been essential to our family's budget. In fact, I'm all for insurance companies creating a "buy one infusion, get one free" punch card. That alone would save my family thousands of dollars a year.

Because couponing is a way of life for me, I believe anything, and I do mean anything, with cost attached to it, can be discounted with a carefully clipped tiny piece of paper. Well, at least I did believe this until a recent run-in with an officer of the peace.

I was unfashionably running on time to our PIDD (primary immune deficiency disease) kids' ear, nose and throat doctor's appointment. Caleb and Molly were nestled in the middle section of our suburbia cross-over Suburban, their lips smacking over sugared snacks used to bribe them to "be good" for the doctor. Cruising along the country road — a typical Idaho highway — I did my best to avoid the frost heaves that make our state's highways and byways famous. As I sipped diet pop, the view of the Sawtooth Mountains' snowcapped peaks calmed my spirit, and the "owyhee's" in my rearview mirror were the masterful bookends to our trip. Nothing, no nothing, is more beautiful or soothing than my Idaho mountainscapes...my thoughts drifted until... The screeching sound of a highway patrolman's siren and the frightening flash of his red lights in my rearview mirror ruined my "Sound of Music" moment.

"Mom!" Caleb hollered. "You gotta pull over!"

Surely this officer of the peace doesn't want me!? I hoped.

I gently glided to the rocky shoulder; the crunch of de-icing material on my tires helped me come to a safe stop. But the officer didn't scream by me as if he were on his way to a really important incident. He was right behind me! Caleb and Molly must have seen the look of terror shooting from my eyeballs, which were fixed on my rearview mirror.

"What do I do!? What do I do!?" I cried in a panic. In my 30-something years of driving, I had never gotten a moving violation! Well, sort of. There was this time I bashed into the back of a 1989 Crystalline Cadillac hearse, but never mind that. A soft knuckle wrap on the window interrupted my hyperactive thoughts.

"Yes, Officer?" I whined. "What did I do?"

"Fifty-seven on a country road," he answered matter-of-factly.

"All I really am doing is taking my poor sick children to their doctor's appointment. I didn't know I was going over the speed limit," I droned on.

My excuse had obviously been heard before as the officer's stoic countenance remained unchanged.

"Your driver's license and registration, please," he continued.

With ease, I handed the officer my license. The registration, however, looked strangely familiar. It had corrugated lines around it much like, ahem, my beloved coupons. Could it be? I wondered. Is this the coupon that folks use to get off with just a

warning? I had to take a chance handing the officer my "coupon."

"Officer, I'd like to use my registration coupon from my insurance company to either reduce or forgive my infraction," I told him.

He took my information and slowly walked back to his squad car, scratching his head in confusion. Minutes later, he approached my car with a goofy grin on his face.

"Here's your license and registration coupon," he said with a smile.

"Am I free to go?" I requested.

"Since this is your first violation and you were only seven miles per hour over the speed limit, I'm letting you off with a warning," he informed me. "Please slow down on the country roads."

"Oh, yes, Officer. Thank you, Sir," I replied.

"Oh, and by the way," he said, looking amused. "Your registration coupon has expired."

Fumbling through Kleenex, various ketchup packets, old suckers and a glove, I found the current registration with the same coupon-ish look to it.

"Will this one work?" I asked.

He responded as if he'd heard it all before: "Yes, but for your information, 'Get one ticket, get out of the next one free' punch cards don't work." ■



CHERYL HAGGARD is a stay-at-home mom and has three children, two of whom have COVID. She and her husband, Mark, also operate Under the Hood Ministries at www.underthehoodministries.org.

Two All Beef Patties...

By Mark T. Haggard

THERE ARE THINGS that cannot be understood: the path of ants underground, the flight path of birds in the air, and the ways of a woman. The first time we got pregnant, just the sight of a bird carcass made Cheryl nauseous, which made it difficult to surprise everyone with our happy announcement at our big family Thanksgiving dinner. We didn't eat any more fowl until after Calvin was born.

A few years later, when our second son, Caleb, was 1 year old, we were forced out of our house by mold. During that time, we became pregnant with Molly, and Cheryl suddenly couldn't eat anything green; it must have been remembrances of the green stachybotrys and aspergillus on our baseboards. We didn't return to eating spinach and asparagus until after our daughter was born.

Not that it bothered me much; I was not one to eat a lot of vegetables growing up. More than once after dinner when I was young, my mother found spoonfuls of peas floating, hidden and uneaten, in my glass of milk. Similarly, during Caleb's formative years, his taste buds did not become attuned to the joys of Brussels sprouts, broccoli or zucchini. We're paying the consequences today.

For some reason, my son only has a taste for red meat. His favorite is in



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the form of hamburgers. He doesn't mind steak or roast beef or an Idaho elk strap. Ham and chicken are fine, and he'll tell you shrimp is "the bomb." But, once you get out of the proteins, it's "slim pickin's."

Caleb will eat other foods as well, just nothing exotic like Mexican or Italian or hot dogs. We have been told that after so many sinus surgeries, he has lost some of his sense of taste. He loves sucking on lemons. At least we will never have to worry about scurvy.

We have recently been reminded that what we eat has much to do with the overall health of our immune systems. Knowing that, we are trying to sway our son into eating less red meat and more of a variety of foods, including fruits and vegetables. But like a stain on my favorite shirt, his eating habits have set in.

Cheryl knows how to order takeout for our three kids: "Two kids' meals and one hamburger with just cheese and ketchup, no lettuce, no tomatoes, no onions, no pickles, no mustard, no mayonnaise, no guacamole, no special sauce." When I order for the kids, I read straight from the menu and the burger shows up with everything on it. Hence, we spend the next 20 minutes scraping the vegetation off and into the "to go" bag.

I need to admit a *mea culpa* here. I have an aversion to pickles and tomatoes, so when my burger shows up, I start desaladizing it as well.

A few weeks ago, my wife suggested to Caleb that, while at school, he should have a lunch with a "variety of different colors."

He took that suggestion to heart.

"Dad, Dad, Dad," he called to me at dinnertime.

"What, Son?" I replied, echoing his enthusiasm, thinking that he had made the football team or aced a test.

"I tried something new at lunch today," he told me.

"Yeah, you forgot your lunch in the refrigerator this morning," I pointed out.

"I know," he lamented.

"Remember how Mom told me I needed to eat foods that were a variety of colors?"

"Yeah," I replied, "like a variety of fruits and vegetables."

"Well, I tried something new today!" he exclaimed.

"That's great, Son," I replied, envisioning his lunch plate with green beans, sliced peaches and a side salad. "What'd you have?"

"Almond M&M's. They were good!" he cried.

I sighed as my chin slumped to my chest. "Great," I muttered.

"Yeah," he replied. "Except I didn't like the green ones."

Add that to the list of green things he won't eat. At least chocolate is good for the immune system. ■



Illustration by Ben Drolet

It's No Miss-Shake

By Ever Fecske



Illustration by Ben Drolet

IN PREVIOUS COLUMNS, I have had no problem sharing ... well ... my problem. My problem is bowel over-regularity. At least that is what I have come to call it during the past four years of the toilet ruling my life. Trapped in this stereotypical controlling relationship, I couldn't go anywhere without checking in with the restroom first. In fact, I would continue to check in between eight and 20 times a day: after I ate, exercised, shopped, sneezed or sat down in a car.

Despite appointment after appointment with my gastrointestinal mediator, three endoscopies and two colonoscopies, we just couldn't figure out a way to make my unhealthy relationship with the lavatory less controlling. I had to try to do something myself! At first, I thought that maybe it was my lifestyle. So I singled out particular

food groups, like dairy, gluten and fat, and removed them from my diet, but nothing seemed to aid in the divide I so needed from this ongoing annoyance.

Recently, my boyfriend, Jim, decided he had to do something about his high cholesterol. To help, I made him oatmeal every morning, and I ate it, too. He hated it! Without sugar, the taste was bland. Then, one day while watching the Food Channel, Jim learned that raw oatmeal was better for lowering cholesterol than cooked. So we created our own recipe with raw oatmeal. Each morning, we now blend together an oatmeal shake and drink. I know what you are thinking: "Drink raw oatmeal? Gross!" I thought the same thing at first. But to my surprise, it was tasty and refreshing, and,

most important of all, my stomach liked it. After a week, my cramping had stopped, the ... um ... consistency was almost normal, and I was only visiting the bathroom between four and eight times a day—a major improvement from my regular 20!

Here's our recipe for one serving: In a blender, add 1 cup raw oats, 1 cup frozen blueberries, one-half banana, 2 tablespoons ground flax seeds and about 1½ cups non-fat milk, or until the dry mixture is covered with milk. Blend until the oats and the blueberries are broken down. If you don't like cow's milk, you can try soy, almond or rice milk, and it tastes just as good.

We chose the ingredients for a reason: oats for lowering cholesterol and heart health, blueberries for antioxidants, flax seeds for omega-3 fatty acid, banana for potassium and taste, and milk for calcium.

While this breakfast shake has helped me improve my gastrointestinal health, that doesn't mean it will help you. However, if you decide to try it, please let me know. I would love to hear from anyone who makes this recipe and has results similar to mine. Happy blending! 🍷



EVER FECSKE was diagnosed with CVID and interstitial lung disease in 2004.

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Side Effects of IG

When patients experience side effects from IG therapy, they often can control them by altering treatment methods or by switching to a different IG product or treatment.

By Kris McFalls and Nancy Creadon, RN

DO THE SIDE effects of medication outweigh the risks of not taking a medication? While the answer to that question will differ depending upon the type of medication, in the case of intravenous immune globulin (IVIG), the answer is, most often, no. Most side effects of IVIG are considered mild, manageable and would not require the discontinuation of therapy, according to the website, www.immunedisease.com. And, patients like Nancy Hoffman know this: The flu-like symptoms, such as fatigue, backaches and headaches that follow an infusion of IG, pale in comparison to the constant bombardment of potentially life-threatening infections she had before the diagnoses of common variable immune deficiency (CVID) and idiopathic thrombocytopenic purpura (ITP). The same could be said for Julianne Dallara, who has chronic inflammatory demyelinating polyneuropathy (CIDP). For her, the benefits of being able to do simple things, such as take a bath without help, work outside the home, take care of her kids or walk instead of riding in a wheelchair, far outweigh the side effects of the IVIG infusions.

All medications come with side effects. And, of course, side effects can be different for all individuals.

For example, according to the CIDP USA Foundation (www.cidpusa.org), females with a history of migraines are more likely to experience headaches with IVIG.

Amy Ehlers, a specialty pharmacist for NuFACTOR, a division of FFF Enterprises, Temecula, Calif., says: "Before starting any medication, patients should discuss with their physician all of the risks and benefits.

Most side effects of IVIG are considered mild, manageable and would not require the discontinuation of therapy.

For most patients, the benefits outweigh the risks, but that isn't always the case. In addition, some side effects are more serious than others and may require more comprehensive patient education or ongoing monitoring." The plain and simple fact about IG is that most patients utilizing the treatment depend on it for survival. So the question is not whether to use IG treatment because of the side effects, but rather, how to deal with the side effects that come with it.

First and most important

First and most important, all side effects should be discussed with the prescribing physician. For serious side effects, which are rare, such as chest pain, difficulties breathing, severe headaches and changes in blood pressure, patients should immediately call 911. Other side effects, such as nausea, mild to moderate headaches, fever, chills, muscle pain, minor rashes and backache, can usually be lessened with some modifications directed by the patient's doctor. Fortunately, most patients experiencing these side effects can be helped by slowing down the rate of infusion. Premedication with acetaminophen, antihistamines or, occasionally, steroids can also help decrease side effects.¹

Hydration the day before, the day of and the day after IG treatment, says Ehlers, also seems to have a direct relationship to the number and severity of reactions: "IG is a viscous fluid rich in antibodies. When infused into a patient, the human body reacts by immediately drawing fluid from other body parts to help tissues absorb the new proteins. If the patient is not well-hydrated, common symptoms of dehydration such as headaches, dry skin/mouth,

fatigue, muscle cramping and dizziness may occur.” Therefore, whether utilizing IVIG or subcutaneous immune globulin (SCIG), it is important to hydrate.

Finding an IG Product or Treatment with Fewer Side Effects

All IG products are made from human plasma, and all manufacturers follow strict protocols for safety. However, not all IG products are made the same. Therefore, if a patient battles side effects, no matter what is done to reduce them, it may be time to try another brand or another method. The patient’s pharmacist and doctor will be able to help find a product that works best for them.

For Nancy, the side effects of IVIG never went away. In addition, Nancy’s problems with venous access required nine to 10 attempts to insert the needle just to get an infusion started. For her, the answer was to switch her method of infusion from intravenous to subcutaneous. With SCIG, the immune globulin is infused in smaller, more frequent doses to allow the body to absorb the fluid more slowly, thus resulting in fewer, if any, side effects. And, because infusing occurs just under the skin into the fat tissue, rather than into a vein, SCIG eliminates the need for intravenous access, as well as dependence on nursing. SCIG has given Nancy independence, which now allows her to travel.

Julienne experienced debilitating migraines with her initial infusions, which prompted her to consider giving up infusions altogether. Instead,

Julienne’s doctor ordered a change in products. In addition, her infusions were altered to start very slowly with increases as tolerated. These changes have nearly eliminated her reactions and have allowed her to do what is most important to any parent—spend precious time with her kids. And, because the IVIG treatments

If a patient still battles side effects, no matter what is done to reduce them, it may be time for them to try another brand or another method.

stopped the progression of her disease, Julienne’s income is up 25 percent, and she no longer has the need for disability.

Dealing with a Lack of IgA

Some patients who have little or no IgA antibodies have experienced anaphylactic or anaphylactoid reactions when given IVIG products that contain moderate amounts of IgA.² As a result, when infused with a product containing IgA, the patient’s body may launch a response to what it perceives as a foreign invader. Some case studies, however, suggest that certain patients may be able to safely infuse subcutaneously, and later transition back to IVIG if desired. One study in particular found that

“immunoglobulin can be given to IgA-deficient patients without side effects when infused subcutaneously... [which] suggests that this route of administration should be recommended for infection-prone IgA-deficient patients.”³ The study’s authors noted, however, that it is “important to stress the need for a careful surveillance and monitoring of these patients when new therapeutic strategies are employed.”

Conclusion

While side effects from IVIG therapy are likely to occur, they can often be mitigated. More importantly, the risks of not using IG are much greater than any side effects that may ensue. The best news is that side effects can be controlled and it’s simply a matter of making changes to deal with them by keeping well-hydrated, by taking additional medications to lessen the effects, or by altering the type of IG products and/or treatment. ■

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1. Ippoliti C, Williams LA, Huber S. Toxicity of rapidly infused concentrated intravenous immune globulin. *Clinical Pharmacology*, 1992;11:1022-1026.
2. Lomax, C. IgA Content in IVIG Products. *IG Living*, August-September 2008, pp32-33.
3. Sundin, U, Nava, S, and Hammarstrom, L. Induction of unresponsiveness against IgA in IgA-deficient patients on subcutaneous immunoglobulin infusion therapy. *Clinical and Experimental Immunology*, 1998; 112: 341-346.

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Creating Green Indoor Environments

By Ronale Tucker Rhodes, MS



With eco-friendliness a growing concern around the world, many people are looking at how they can be a part of improving not only the outdoor environment, but also their own indoor environment. Indoor air quality is especially a concern for patients with immune system disorders. Irritants such as strong chemicals, dust mites, airborne bacteria, viruses and mold can irritate respiratory passageways, providing mucous-rich breeding grounds for potentially hard-to-treat infections.

A new study by researchers at Seattle Children's Hospital and the University of Washington (UW) identifies a connection between allergies and autoimmune diseases. Published in the April 1, 2007, edition of *Nature Immunology*, the study "implies that allergic and inflammatory diseases may actually trigger autoimmune diseases by relaxing the controls that normally eliminate newly produced, self-reactive B cells. This is important because many autoimmune diseases are

caused by self-reactive antibodies produced by such B cells," said Dr. David Rawlings, lead researcher and section head of immunology at Seattle Children's Hospital and the UW.

According to the Environmental Protection Agency (EPA), indoor pollution is often tens or hundreds of times higher than outdoor pollution. And, since people spend 90 percent of their time indoors, purifying homes from bacteria and viruses that may exist in the air, water and on household surfaces can help decrease the exposure to risk factors that can lead to infection.

Green Cleaning to the Rescue

In the quest to keep the indoor environment clean, traditional home cleaning products often create more harm than good. The fumes and residues they produce can exacerbate allergies and asthma, and they can be poisonous for children and pets.

How can it be determined whether a product is toxic? "By law, all cleaning products sold in the U.S. and Canada must be labeled with appropriate cautions and warnings about any acutely hazardous, poisonous or toxic ingredients," according to the article, "Green Cleaning" (HouseKeepingChannel.com). "However, also by law, manufacturers do not need to list chemistries that are proprietary or chemicals that are not among the 'active' cleaning ingredients. Many of these hidden substances may be hazardous to your health over time or in combination with other chemicals in the environment."

Put simply, the website Planet Green (planetgreen.discovery.com) advises individuals to look for products that are non-toxic, biodegradable and made from renewable resources (not petroleum). However, it also advises: "If designer labels aren't for you, home-mixed cleaners can get the job done and then some. Vinegar and baking soda can be used to clean almost anything. Mix in a little warm water with either of these, and you've got yourself an all-purpose cleaner."

Purifying the Air

With so much time spent indoors, purifying the air in the home should be a priority. A variety of air purifiers are available for purchase. However, Mother Nature is also a solution. Having plants indoors increases oxygen production and zaps up extra carbon dioxide, purifying the air. In the 1980s, NASA conducted a study, in conjunction with the Associated Landscape Contractors of America, which found certain indoor plants purify the air better than others, and

that some plants take specific pollutants out of the air more so than other plants. The book, *How to Grow Fresh Air: 50 Houseplants That Purify Your Home or Office*, by B.C. "Bill" Wolverton, an environmental scientist working with the U.S. military to clean up the environmental messes left by biological warfare centers, explains which plants and varieties remove the most toxins.

Indoor air pollutants also can be decreased by ensuring there is adequate ventilation inside the home. According to the EPA's booklet, *The Inside Story: A Guide to Indoor Air Quality*, signs of inadequate ventilation include "moisture condensation on windows or walls, smelly or stuffy air, dirty central heating and air cooling equipment, and areas where books, shoes or other items become moldy." If odors are noticeable upon entering a household, it is likely that ventilation is an issue.

Other ways to purify the air include throwing away pet waste by cleaning out the cat's litter box and picking up after the dog, changing out air filters and using natural home furnishings and carpet.

A new study... identifies a connection between allergies and autoimmune diseases.

Taking Control of Your Environment

According to the Planet Green website, there are 63 synthetic chemical products found in the average American home, which translates to roughly 10 gallons of harmful chemicals. Individuals with primary or autoimmune diseases are particularly susceptible to pollutants in their home environments, so for them, creating a healthy and green indoor environment can be their first line of defense against illness.

Directory of Green Living Products

Below is a list of companies that provide lines of green living products, as well as descriptions of their offerings. For more information, contact the companies directly.

AllergyBuyersClub.com

Since 1998, AllergyBuyersClub.com has specialized in allergy relief products and education on the control and prevention of allergies, sinusitis and asthma. Products listed on the company's website are natural, green and hypoallergenic, and are designed to appeal to those who wish to have a clean, healthy home that is free of pollutants.

The company tests, reviews and rates all listed products to ensure they meet stringent standards.

(888) 236-7231; www.allergybuyersclub.com

Dyson

Dyson manufactures asthma and allergy friendly vacuum cleaners that use patented Root Cyclone™ technology ➤

designed to remove 99.9 percent of dust, dirt and allergens. In addition, the cleaners feature a HEPA (High Efficiency Particulate Air) filter to capture particles as small as 0.1 microns (the equivalent to a single particle of cigarette smoke). Dyson vacuums have passed a series of stringent tests based on an extension of existing vacuum cleaner industry standards developed by the American Society for Testing and Materials (ASTM), as well as the International Electrotechnical Commission (IEC).

(888) 693-9766; www.dyson.com

GreenCupboards

GreenCupboards offers household products that are environmentally friendly. The company is dedicated to researching products that are the “greenest” and most effective, and then bundles them in what they call “Cupboards.” All of the products have been tested and certified on the basis of five criteria: ingredients, toxicity, efficacy, manufacturing processes and packaging. Lines currently offered include kitchen, bathroom, laundry, dog and cat products. The company donates 1 percent of its pre-tax profits to non-profit organizations that promote a cleaner, self-sustaining environment.

(877) 838-3131; www.greencupboards.com

Nikken

Nikken manufactures air and water purifiers. Air purifiers include the Air Wellness Power5™ Pro and the Air Wellness Traveler. Both use multiple stages of filtration to reduce contaminants — including HEPA filters, like those in laboratories and hospital operating rooms. In addition, they produce negative ions to replicate the atmosphere found in forests and near waterfalls, without producing ozone. Both models can be set to detect the presence of contaminants and operate automatically. PiMag Water Technology comes in a variety of systems — from in-home water, to water bottles and shower systems — and features several levels of filtration to reduce contaminants without adding chemicals.

(800) 669-8859; www.nikken.com/onlinecatalog

PureZone

The PureZone Pillow system is a hypoallergenic pillow designed to remove airborne allergens in the breathing zone surrounding a person’s head as they sleep. The portable amenity uses a small, ultra-quiet air-blower to

connect to a HEPA filter to remove allergens such as dust, pollen and pet dander. It can be set up on any bed with any type of pillow.

(877) 787-3977; www.purezone.com

RabbitAir

RabbitAir manufactures a line of air purifiers that use either BioGS™ or MinusA2™ technology. The BioGS HEPA filter is made of a bio-engineered fiber material that traps and destroys allergens such as pet epithelia, dust mites and pollen. It has five different speeds, is energy-efficient (consuming 33 watts at the highest speed), can eliminate most common household odors and lasts up to three years. The MinusA2 uses a nano-silver electrostatic pre-filter that kills germs and traps pet hair, large-size allergens and dust, and is also very effective against most common bacteria, yeasts, molds and fungi bacteria. It also has five different speeds, as well as four modes of operation, is energy-efficient (consuming 47 watts at turbo speed), can eliminate most of the common household odors and lasts up to two years.

(888) 866-8622; www.rabbitair.com

Seventh Generation

Seventh Generation brand-name products include non-chlorine bleached, 100 percent recycled paper towels, bathroom and facial tissues, and napkins; non-toxic, phosphate-free cleaning, dish and laundry products; plastic trash bags made from recycled plastic; chlorine-free baby diapers, training pants and baby wipes; and chlorine-free feminine care products, including organic cotton tampons. The company dedicates 10 percent of its profits to non-profit community, environmental, health and responsible business organizations working for positive change.

(800) 456-1191; www.seventhgeneration.com

Shaklee

Shaklee offers Get Clean Healthy Home products. Its Get Clean Starter Kit contains a variety of cleaning products, from cleaning concentrate and wipes, disinfecting wipes, laundry products, hand washes, dishwasher concentrates, etc. The kit also comes with accessories, including an organizer caddy, spray bottles, dispenser bottles and pumps, measuring scoops, scrubbing pads and more.

(800) 742-5533; www.shaklee.com50444.html

For a more comprehensive list of resources, visit the Resources page at www.IGLiving.com.

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 (CIDP)

Websites

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

Online Peer Support

- 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

- Office of Rare Diseases (catalog of online resources) <http://rarediseases.info.nih.gov/GARD/Disease.aspx?PageID=4&diseaseID=6389>
- Clinical Reference from eMedicine: www.emedicine.com/ped/topic721.htm

Online Peer Support

- Evans Syndrome Research and Support Group: www.evanssyndrome.net

Guillain-Barré Syndrome (GBS)

Websites and Chat Rooms

- The GBS/CIDP Foundation International, www.gbs-cidp.org, has 23,000 members in 160 chapters on five continents. (610) 667-0131
- 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

- The GBS/CIDP Foundation International Discussion Forums provide the opportunity to talk to other GBS patients and learn more about ways to manage the illness: www.gbs-cidp.org/forums.

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 www.mayoclinic.com/health/idiopathic-thrombocytopenic-purpura/DS00844
- 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 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: www.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>
- 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/rarediseasespl/pemphigus05.htm>

Peripheral Neuropathy (PN)

Websites



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

- 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.calgarypn.org
- 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



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

Jeffrey Modell Foundation

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

- 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.
- Rainbow Allergy-Immunology, www.rainbowbabies.org/immunology, provides comprehensive diagnostic, therapeutic and consultative services for children and adults with immunologic diseases. For patient information about subcutaneous IG therapy: www.rainbowbabies.org/subcu.
- Support for those with PID in the New England area: www.teamhope.info

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 www3.niaid.nih.gov/healthscience/healthtopics/immuneSystem/PDF/thelmmunesystem.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
- Rhode Island peer group: rhodeislandpidd@yahoo.com

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: <http://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.

Books and Articles

- “A Flower Grows in Stone: The Diary of a Life in Progress,” a firsthand account of her struggle with Stiff-Person/Moersch Woltman Syndrome, is written by

first-time author Anisah Hassan. Available from Llumina Press, Ingram, and Baker & Taylor, www.llumina.com.

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/pdfs/flebo_14Jun05.pdf
- IVIG Gammagard Liquid www.gammagardliquid.com
- IVIG Gammagard S/D www.immunedisease.com
- IVIG Gamunex www.gamunex.com
- IVIG Octagam www.octapharma.com/corporate/03_products_and_therapeutic_areas/01_immunoglobulin_product_line/03_octagam.php
- IVIG Privigen www.privigen.com
- 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.needpsi.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: <http://idea.ed.gov/explore/home>
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/office/news/2008/discrimdisab.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.ada.gov.

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 Brezsny, 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.rmsmedicalproducts.com
- Norfolk Medical: www.norfolkmedical.com

Medical Research Studies

- On the official website for the National Institutes of Health patient recruitment program, you'll find summaries and criteria for studies as well as be able 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.aaaai.org
- 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!