



Nutrition Therapies for Autoimmune Diseases

Antibiotics:

Avoiding Interactions

Subcutaneous IG Therapy:

An Alternative

H1N1 (Swine) Flu:

Knowing the Risks



Up Front

5 Editorial
By Ronale Tucker Rhodes, MS

6 Contributors
Experts in this issue

Did You Know?

7 Industry News
Research, science, product
and insurance updates

10 Legal Issues
To Disclose or Not to Disclose?
That Is the Question!
By Jennifer C. Jaff, Esq.

12 Medical News
Do Immune Disorders Increase
the Risk of H1N1 (Swine) Flu?
By Ronale Tucker Rhodes, MS

Lifestyle

34 Let's Talk
By Shirley German Vulpe, EdD

36 Ask Kris
By Kris McFalls

37 Choices
By Ever Fecske

38 An Audience of One
By Cheryl L. Haggard

40 O Captain, My Captain
By Mark T. Haggard

42 To Disclose or Not to Disclose?
By Jennifer Kester

Features

**14 Nutrition Therapies for
Autoimmune Conditions**
By Jessica Schulman, PhD, MPH, RD, CLE

20 Antibiotics: Avoiding Interactions
By Amy Ehlers, BS, PharmD, BCPS

**24 Subcutaneous IG Therapy:
An Alternative**
By Mark R. Stein, MD

**28 Understanding and Coping with
Wiskott-Aldrich Syndrome (WAS)**
By Deena Marie Biengardo

Sources

44 Product Directory
An Overview of Pumps
By Nancy Creadon, RN

46 Book Corner
New and useful book titles

47 Resource Center
Community foundations, associations,
forums and other resources



About *IG Living*

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

IG Living, published bimonthly, is a community service provided by FFF Enterprises, 41093 County Center Drive, Temecula, CA 92591, (800) 843-7477 x1143, fax (951) 699-9655.

Subscriptions to *IG Living* are free, and readers may subscribe at www.IGLiving.com or by calling (800) 843-7477 x1362.

The opinions expressed in *IG Living* are those of the authors alone and do not represent the opinions, policies or positions of FFF Enterprises, the Board of Directors, the *IG Living* Advisory Board or editorial staff. This material is provided for general information only. FFF Enterprises does not give medical advice or engage in the practice of medicine. FFF Enterprises under no circumstances recommends any particular treatment for any individual and in all cases recommends that individuals consult with a physician before pursuing any course of treatment.

All manuscripts should be submitted in MS Word, in Arial font. Manuscripts should be between 650 and 1,300 words in length, with unjustified margins and without any other formatting. Submission guidelines are available for download from the Contact Us page on www.IGLiving.com. Email manuscripts to editor@IGLiving.com. *IG Living* retains the right to edit submissions. The contents of each submission and their accuracy are the responsibility of the author(s) and must be original work that has not been, nor will be, published elsewhere, without the written permission of *IG Living*. A copyright agreement attesting to this and transferring copyright to FFF Enterprises will be required. Acceptance of advertising for products and services in *IG Living* in no way constitutes endorsement by FFF Enterprises. ©2009 FFF Enterprises Inc.

Advertising in *IG Living*

IG Living Magazine is read by 30,000 subscribers who are patients who depend upon immune globulin products and their healthcare providers. For information about advertising in *IG Living*, download a media kit at www.igliving.com/web_pages/advertising.html. Or, contact our advertising specialist: Trudie Mitschang, (800) 843-7477, ext. 1340, trmitschang@igliving.com.

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

A community service from
FFF Enterprises, Inc.

Advisory Board

Nancy Creadon, RN
Vice President
VaxAmerica

Erika Lawrence, PhD
Associate Professor
Department of Psychology
University of Iowa

Todd Levine, MD
Director, Department of Neurophysiology
Good Samaritan Hospital, Phoenix
Assistant Professor of Clinical Neurology
University of Arizona

Fred Modell
Co-founder of the
Jeffrey Modell Foundation

Marc Riedl, MD, MS
Assistant Professor
Department of Medicine
Clinical Immunology and Allergy
UCLA, David Geffen School of Medicine

Publisher **Patrick M. Schmidt**
Editor **Ronale Tucker Rhodes, MS**
Assistant Editor **Cheryl Brooks**
Proofreader **Jackie Logue**
Creative Director **Sheryl Perez**
Artistic Director **Allan Bean**
Graphic Artists **Allan Bean**
Ben Drolet

Contributing Writers

Deena Marie Biengardo
Nancy Creadon, RN
Amy Ehlers, BS, PharmD, BCPS
Ever Fecske
Cheryl L. Haggard
Mark T. Haggard
Jennifer Kester
Jennifer C. Jaff, Esq.
Kris McFalls
Jessica Schulman, PhD, MPH, RD, CLE
Mark R. Stein, MD
Shirley German Vulpe, EdD

©2009 FFF Enterprises Inc. All rights reserved.
Please direct editorial, advertising and
marketing communications to
41093 County Center Drive
Temecula, CA 92591
Ph: (800) 843-7477
Email: editor@IGLiving.com
www.IGLiving.com

Get Involved!

IN THE JUNE-JULY issue of *IG Living*, we reported on the latest IVIG bill that was introduced in the House and Senate this past April. This is the second year that legislation to fix IVIG access and reimbursement has been introduced in Congress. Last year, it failed to pass for a variety of reasons, but certainly among them is the overwhelming volume of thousands of bills that Congress faces each year. With such daunting competition, it is highly likely that this year's IVIG bill will once again fall short of receiving a positive response from Congress unless it is given the attention it deserves. How do we ensure that? By getting involved.

The importance of making our voices heard was a main theme at this year's biennial Immune Deficiency Foundation (IDF) conference, held June 18-20 in Orlando. IDF has been a force behind many IVIG-related bills, and this year, for the first time, joined with 18 other organizations to sponsor the current bill. The strategic importance of this combined effort cannot be overstated. Previous federal legislative attempts, as well as other state legislative actions, were independently introduced by IDF and other organizations and lacked the collaborative impact that inspires positive legislative attention.

While debate about the IVIG bill was due to begin on July 6th, it is still not too late to show support for the bill, even at, and especially at, the individual level. All major patient organizations sponsoring the current IVIG bill request patients and their families get involved. Obviously, appealing to your local members of Congress is the first step. To access a locator to find your local Congressional delegates, go to the *IG Living* website where you can also find a sample letter you can use to encourage them to support the bill (www.igliving.com/web_pages/action_items.html).

The IDF website also has useful resources: a zip-code locator to find your local Congressional

delegates, as well as a letter composed by IDF, which can be supplemented with personal information (www.primaryimmune.org/action_alert.htm). That letter can either be emailed directly from the IDF website, or it can be printed for mailing. If you decide to write your own letter, be sure to keep it to one page and to ask your representatives for their support. In addition to writing your representatives, it is recommended that you also call and/or visit them. Be sure to develop a strong message, practice it and make it personal.

You can make a difference! As Larry LaMotte, an IDF representative, said at the conference's public policy session, members of Congress are just like you and me. They all have to get out of bed, they go to work, they have the same kinds of issues that we all face. There's absolutely no reason to be intimidated by their position. In fact, just the opposite: We should expect not only that they be interested in the issues important to us (their constituents), they should be answerable to us. Remember, we pay their salaries. So, get involved and make a difference. Let's ensure that you and others in our community have access to much-needed IG treatments.

We hope you enjoy this issue of *IG Living* and the topics we focus on this month, including nutrition, antibiotic interactions, subcutaneous infusion and more. As always, let us know your thoughts about the content and if you have suggestions for future articles. ■

To your health,



Ronale Tucker Rhodes, MS, Editor



Contributing Experts



DEENA MARIE BIENGARDO
Freelance Writer

Understanding and Coping with Wiskott-Aldrich Syndrome (WAS)

"Because WAS affects a very small number of people, it has received little attention, despite its devastating effects."



NANCY CREADON, RN
Vice President, VaxAmerica

An Overview of Pumps

"Infusion pumps can be programmed to provide continuous infusions, intermittent infusions or bolus infusions."



AMY EHLERS, BS, PHARMD, BCPS
*Director of Pharmacy,
NuFACTOR Specialty Pharmacy*

Antibiotics: Avoiding Interactions

"The single, largest group of medications, antibiotics, can have side effects and interactions that can range from mild and inconvenient, to serious and potentially life-threatening."



JENNIFER C. JAFF, ESQ.
*Founder and Executive Director,
Advocacy for Patients with Chronic Illness Inc.*

To Disclose or Not to Disclose? That Is the Question!

"You have no legal obligation whatsoever to tell an employer or prospective employer that you have a chronic illness — ever."



JENNIFER KESTER
Freelance Writer

To Disclose or Not to Disclose

"Many wrestle with the decision of when — or whether — to reveal their medical condition to others."



JESSICA SCHULMAN, PHD, MPH, RD, CLE
Credentialed Dietitian and Lactation Educator

Nutrition Therapies for Autoimmune Conditions

"There is no single anti-inflammatory diet for everyone; a specialized diet that helps one person may be like poison for the next."



MARK R. STEIN, MD
*Private Practice,
Allergy Associates of the Palm Beaches*

Subcutaneous IG Therapy: An Alternative

"SCIG allows patients to self administer infusions at home, and may be especially appropriate for people with PID."

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.

Did You Know?

Research

Study Seeks Chronically Ill Patients for Survey

Individuals with chronic illnesses and their caregivers are being asked to participate in a study about the obstacles they face, interventions that do and do not work, and ways in which the research and clinical trials conducted by the National Institutes of Health (NIH) may be helpful. The study is being conducted by the Advocacy for Patients with Chronic Illness Inc.

and the University of Michigan Center for Managing Chronic Disease, made possible by a grant by the NIH.

Participants must be at least 18 years old and either have a chronic illness such as Crohn's disease, ulcerative colitis, rheumatoid arthritis, fibromyalgia, multiple sclerosis, immune deficiency or other chronic illness, or be a caregiver to an individual

affected by one of these illnesses. The study is an online survey created with the help of 12 patients and caregivers. Those unable to take the survey online can be interviewed by phone. A total of 1,500 individuals is sought for the survey. For more information, contact Jennifer Jaff and the Advocacy for Patients with Chronic Illness at (860) 674-1370. ■

Patients

CIDD Family Gets Extreme Makeover

Molly and Maggie Cerda are healthier than they have ever been. The sisters, along with their mother, Terri, have combined immune deficiency disease (CIDD), and had been living in a house that had mold in the walls, as well as allergens, structural problems and an outdated plumbing system. For patients with CIDD, these conditions can exacerbate their illness, causing coughing episodes and even a shutdown of the lungs. Now, thanks to ABC's "Extreme Makeover: Home Edition," those issues are in the past. The Cerdas were chosen for

need, both in their local community and around the country.

As part of the makeover, the home was demolished and rebuilt from the ground up in seven days. Hundreds of volunteers from their community worked on the home, new furniture was donated, as was three years of security service, a year of pest control and other donations. The family was reintroduced to the house on March 19. "Our life is going to be different because the air inside this house is completely clean," Molly Cerda said. "That helps my lungs and will make us even healthier, to the point where we might not have to wear masks anymore." The "Extreme Makeover: Home Edition" aired on May 10 on ABC, and the full episode can be viewed at <http://abc.go.com/primetime/xtremehome/>.

IDF is also featured on ABC's "A Better Community" website in association with the Cerda family episode to let viewers know how they can support IDF and make a difference in the lives of families who are affected by CIDD. More information can be found at <http://abc.go.com/abettercommunity/>. ■

Research

State IVIG Bill Introduced

The Legislative Task Force on Peripheral Neuropathy convened in Sacramento in March to submit recommendations to the California Legislature on public and physician awareness of the disease, to promote early diagnosis and to address access to proper treatment. Specifically, the task force recommended that the Legislature pass legislation to enact state standards of care for IVIG, specifying what is required to provide IVIG, as well as requiring medical institutions throughout the state to either stock IVIG or to have direct product access to obtain IVIG in a short period of time. In addition, it recommended that standards "require insurance coverage for the screening and testing procedures necessary to detect peripheral neuropathies," and that "insurers cover all brands of IVIG and other treatments that may be required for the treatment of peripheral neuropathies." ■



a home makeover because of their personal, financial and health-related difficulties resulting from having CIDD, as well as their volunteer work for the Immune Deficiency Foundation (IDF) and for families in

Did You Know?

Medicine

Eligibility Rules for Discounts on Some Drugs Eased

With people struggling to pay for prescriptions, especially in light of today's economy, many drug companies are easing the eligibility rules for discounts.

In March 2009, Merck increased the income eligibility of its assistance plan for its diabetes and asthma drugs to 400 percent of the poverty level (\$43,320 or less for individuals; \$58,280 or less for couples; \$88,200 or less for a family of four), from its previous 200 percent rate. Abbott launched a program to help patients pay for its injectable autoimmune disease drug, which results in many people not having to pay more than about \$5 per month if they have insurance coverage.

The income rules for the Together Rx Access discount drug card were changed to \$45,000 a year for a single person (up from \$30,000) and increased to \$105,000 for a family of five (up from \$70,000). The free card, which is sponsored by Pfizer and Novartis, benefits legal U.S. residents without public or private prescription coverage who don't qualify for Medicare.

Rx Outreach has added more than 100 drugs to the nearly 300 generics that it will provide for anyone with a U.S. address and who earns no more than 300 percent of the federal poverty level (\$32,490 for an individual; \$66,150 for a family of four).

While these are just a mention of a few, information on all drug company assistance programs can be found at www.rxassist.org or (401) 729-3284. ■



Research

Gene Therapy Successful for Curing SCID

Eight out of 10 children with severe combined immunodeficiency (SCID) have been determined to be cured, according to a study published in the Jan. 26, 2009, issue of the *New England Journal of Medicine*. The study involved a different, less-common form of SCID (also known as bubble boy disease), which arises in babies with a genetic

defect that leaves them deficient of an enzyme called adenosine deaminase. Gene therapy for this study was performed in Italy and Israel, and the 10 children are alive now two to eight years later, with only two still requiring treatment. In addition, while recent studies found that gene therapy also carried a risk of leukemia, none of the children in this study showed signs of leukemia or other health problems from the therapy. ■

Did You Know?

In a recent experiment, mirthful laughter had a very positive effect on diabetes patients; their levels of 'good' cholesterol climbed, while inflammation levels notably decreased.

— **Study by Loma Linda University Preventive Care Specialist and Psychoneuroimmunologist Lee Berk, DrPH, MPH**

Disease

Raise Money with the A-T CureTour

Individuals and organizations are being sought to host a fundraiser for ataxia-telangiectasia (A-T). The fundraiser is a continuation of the A-T CureTour of 2007 during which ultra-runner Tim Borland ran 63 marathons in 63 consecutive days, spanning more than 14,000 miles, 29 states, one Canadian province and 63 communities where A-T children live. During Borland's journey, he pushed a mobility jogging stroller that either carried an A-T child or a banner bearing the name of a child

who died. The goal was to raise awareness and funds to help find a cure for children battling this rare, terminal disease. Two filmmakers followed Borland every step of the way, documenting his journey and that of families coping with the disease. The documentary, titled "FEAT," can be shown to raise additional funds through ticket sales. To host a screening in your area, contact fundraising@atcp.org. More information about "FEAT" can be found at www.featmovie.com. ■

Disease

Vaccine Causes Infection in Infants with SCID

The rotavirus vaccine, which the Centers for Disease Control and Prevention (CDC) recommends be given to all infants at 2, 4 and 6 months of age, can cause infection in infants with severe immunodeficiencies. According to Niraj C. Patel, MD, of Baylor College of Medicine in Houston, two infants receiving the first two of three scheduled doses of the live, attenuated-virus rotavirus vaccine (RotaTeq) developed infections traced to the product. These are the first reported cases of infection caused by the vaccine.

In one case, a girl was hospitalized for pneumonia and respiratory infection from 2 weeks to 2 months of age. After the second dose of the rotavirus vaccine, she was rehospitalized with diarrhea, acidosis and failure to thrive. In the other case, a boy developed

Children with primary immune deficiencies, especially those with defective T cells, X-linked agammaglobulinemia, ataxia telangiectasia, severe combined immune deficiency (SCID) and Wiskott-Aldrich syndrome, should not receive live vaccines, such as measles, mumps, rotavirus, BCG and chickenpox (varicella) vaccines.¹ However, neither of the children who developed infections from the rotavirus vaccine had been diagnosed with SCID until after infection. SCID occurs in about one in 500,000 to one million births. And, even though many organizations are advocating to include nationwide mandatory newborn screening for SCID, there is currently only one state, Wisconsin, that does. Massachusetts has offered screening on a voluntary basis as of February 2009.



diarrhea, dehydration and shock six days after the second vaccination. Molecular analyses showed that the vaccine caused the infections, said Patel.

It is estimated to cost \$2.3 million to treat a diagnosed SCID patient after problems arise, versus \$378,000 for diagnosing an infant at birth before problems arise.² ■

1. ImmuneDisease.com. FAQs on Primary Immunodeficiency. Accessed at <http://www.immunedisease.com/patients-and-families/about-pi/faqs>.
2. Spigel, S. Newborn Screening for Primary Immunodeficiency Disease. OLR Research Report. Accessed at <http://www.cga.ct.gov/2008/rpt/2008-R-0564.htm>.

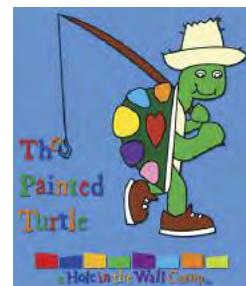
Patients

Free Camp for PIDD Families

A free weekend for kids ages 6 to 17 with a PIDD diagnosis and their families is being hosted by The Painted Turtle, a member of Paul Newman's Association of Hole in the Wall Camps in Lake Hughes, Calif. The Fall Family Weekend, which will be held September 25 through 27, invites families who are living with the challenges of caring for a PIDD child to come to camp and participate in a weekend that emphasizes fun, team building and self-discovery. Activities include boating, fishing, ropes courses, horseback riding, swimming, woodshop and arts and crafts.

The camp has a full-time medical staff who are "joined each session by volunteer medical professionals who generously commit their time and talents to help care for these special kids," says Rosalyn Sayer, camper recruiter and community relations assistant for The Painted Turtle. However, explains Sayer, while constant awareness is given to the medical needs of campers, they have intentionally set out to remove any hint of a medical presence. "When campers visit the medical clinic at camp, [known as] The Well Shell," explains Sayer, "they will find colorful walls, windows overlooking the sparkling lake and a giant domed turtle shell ceiling overhead."

The camp is open to a limited number of families and entry is on a first-come first-serve basis. For more information, visit The Painted Turtle website at www.thepaintedturtle.org, or contact Sayer at rosalyns@thepaintedturtle.org. ■



To Disclose or Not to Disclose? That is the Question!

By Jennifer C. Jaff, Esq.

While individuals are not legally required to disclose if they have a medical condition, certain information will need to be disclosed if seeking accommodations under the ADA or FMLA leave.



When should you tell an employer or prospective employer that you have an immune deficiency or autoimmune disease? The answer is pretty straightforward, in my view: You have no legal obligation whatsoever to tell an employer or prospective employer that you have a chronic illness — ever. Prospective employers are not permitted to ask questions that would force you to disclose this information, and you are not obligated to tell them.

There are, however, circumstances in which disclosure to an employer is necessary. First, if you are asking for reasonable accommodations under the Americans with Disabilities Act (ADA), you have to give your employer enough medical information to:

- 1) establish that you have a disability

and, thus, are covered by the ADA, and 2) demonstrate why accommodations are necessary and what accommodations are needed.

For example, if you have an immune deficiency or other illness, you will have to first establish that your illness is a disability under the ADA. There can be little, if any, question that an immune deficiency is a disability now that the 2008 amendments to the ADA have been passed. A disability is defined as a substantial limitation on a major life activity. The 2008 amendments state that bodily functions such as the immune system are major life activities, and episodic illnesses that are disabling when active are disabling when in remission. On the other hand, whether autoimmune diseases constitute a disability will depend on the nature and extent of the illness. If you have a neuropathy that substantially limits your ability to walk, for example, you will meet the test. In either case, you will have to prove that you have a disability by submitting at least a note from your doctor and, possibly, confirming medical records.

Next, if you are seeking accommodations, you will have to provide enough medical information to allow your employer to engage in an “interactive process” with you to satisfy the accommodations you need. Let’s say, for example, that you

need a flexible schedule so that you can have time during the day to receive IVIG. Or, perhaps you need to be seated away from other employees with communicable illnesses. At least a doctor’s note and, possibly, supporting medical records will be needed to establish your need to be infused during work hours, or that your risk of catching infections is greater than the norm. Once you submit this note along with a written request for accommodation, your employer either will grant the accommodation or engage in an interactive process to see if you can be accommodated by other means. However, once your employer acknowledges that you are disabled, there must be an interactive process; the employer can’t just say no.

The second reason to disclose your immune deficiency in the workplace is if you are seeking leave under the Family and Medical Leave Act (FMLA). The FMLA permits an employee to take as much as 12 weeks of unpaid leave per year for treatment of a “serious medical condition.” A “serious medical condition” is more easily shown than a disability under the ADA. Under the FMLA, you do not have to provide medical records; you just need a “medical certification,” which can be nothing fancier than a doctor’s note. A “serious health condition” is defined as an illness, injury, impairment, or physical or

mental condition that involves a period of incapacity requiring inpatient treatment; continuing treatment by a healthcare provider of a condition lasting more than three consecutive days; or a chronic condition that continues over an extended period of time, requires repeated visits to a healthcare provider, and may involve occasional episodes of incapacity. Any immune deficiency or autoimmune disease should meet this test, and your doctor will need to specifically state that is what you have. Once you have obtained medical documentation, you simply would submit it along with a written request for FMLA leave, and your request should be granted. The 12 weeks of leave can be taken intermittently.

Finally, how much information about your disease should you disclose? In my opinion: as little as possible.

You may feel that your employer will be more sympathetic if you tell them everything, but this generally is not the case.

You may feel that your employer will be more sympathetic if you tell them everything, but this generally is not the case. Even well-meaning employers

may worry about your reliability if they think you're very ill. Even if your employer wants to be understanding, that little kernel of doubt may sneak into the employer-employee relationship. To avoid that to the extent possible, disclose only what you need to disclose in order to obtain accommodations or FMLA leave. Beyond that, your illness is your own business. ■

JENNIFER C. JAFF, Esq., is the founder and executive director of Advocacy for Patients with Chronic Illness Inc., and a patient with two serious chronic illnesses. Previously, she was a trial lawyer and law professor.

Editor's Note: For a discussion about the personal reasons to disclose, refer to the story on page 42.

Do Immune Disorders Increase the Risk of H1N1 (Swine) Flu?

By Ronale Tucker Rhodes, MS

Are individuals with immune disorders more susceptible to catching the new H1N1 flu? While this question is likely being asked by many in the IG community, especially in light of the fact that those with underlying health conditions are experiencing the most severe reactions to this flu, individuals with immune deficiencies and autoimmune diseases are no more susceptible to the H1N1 flu than any other flu. However, those who catch the virus do have a greater susceptibility for symptoms to become more severe. Therefore, it is especially important for this population to protect themselves from contracting the flu.

What Is the H1N1 Flu?

H1N1 flu is a common respiratory disease of pigs. H1N1 flu viruses do not normally infect humans, but can be transmitted when people handle (but not eat) infected pigs; the infection is now increasingly being passed from person to person. This new flu is a mixture of swine viruses and elements of human and bird flu. It has symptoms very similar to the seasonal flu, with severity also ranging from mild to severe. Symptoms include fever, cough, sore throat, body aches, chills

and fatigue. However, it has been reported that the H1N1 flu also has caused diarrhea and vomiting in some people, symptoms that are not typical of the seasonal flu bug.

have the holes that viruses seek out, making them more vulnerable to the havoc a virus can cause once it has entered the body. And, because gastrointestinal tract and sinus infections

The image shows the letters 'H1N1' in a large, bold, 3D font. The letters are a dark green color and are set against a light green background. The letters are slightly shadowed, giving them a three-dimensional appearance as if they are floating or standing on a surface.

Are H1N1 Symptoms More Dangerous?

Individuals with immune disorders (along with the elderly and young children) are at greatest risk for severe illness from the flu. Because their immune systems are compromised and they are more likely to have lung, circulatory or neurological impairments, their ability to fight off the flu is diminished, and the likelihood that their symptoms will develop into something more life-threatening is greater. A good analogy would be to think of viruses as mice. Mice would rather find a hole in the fence than make one of their own. People with immune disorders are more likely to

are common in IG patients, those systems become more vulnerable once the virus has invaded the body. A patient already more vulnerable needs to be judicious about medical follow-through when any new symptoms arise.

What Are the Defenses Against H1N1 Flu?

Flu viruses are always changing. Sometimes they change from when the annual flu vaccine is recommended and the beginning of the flu season; they can even change during a flu season. When flu viruses change, they may no longer closely match viruses used to make that season's flu

vaccine, which can make the vaccine less effective. But even when this happens, the first defense against contracting influenza is the annual flu vaccine, as it can still offer protection. That's why the Centers for Disease Control and Prevention (CDC) recommends getting a flu vaccination every year, even when there is a less-than-ideal match between the viruses used to make the vaccine and those causing illness.¹ Vaccination is especially important for people at higher risk for serious flu-related complications and for people who come into close contact with them.

The CDC also recommends the use of an inactivated (killed) influenza virus vaccine for patients with a weakened immune system and their family members, rather than the live, attenuated (weakened) influenza virus (LAIV) vaccine, commonly known as FluMist.² However, it should be noted that the annual seasonal flu vaccine, which is a killed vaccine, may not work as well for immune disorder patients as it does for the rest of the population.³

While no vaccine for the H1N1 flu exists yet, this virus is known to be an influenza A virus, and the annual flu vaccine contains influenza A proteins. Previous immunity to these proteins doesn't offer total protection, but it may help protect against the H1N1 flu virus. Patients with immune disorders may also be provided a small amount of protection against the H1N1 flu with the use of immune globulin.³

Reducing exposure to the flu virus is a second defense. If worried about contracting the flu, individuals should avoid crowded places such as malls,

pay close attention to personal hygiene, such as hand washing, and keep abreast of current reports by the media and governmental agencies.

If individuals believe they have come into contact with the flu virus, two antiviral drugs, Tamiflu and Relenza, can help to prevent it from developing. More commonly, however, these two drugs are used to treat the flu and are typically useful if taken within 48 hours of the onset of symptoms.

Patients with immune disorders may also be provided a small amount of protection against the H1N1 flu with the use of immune globulin.

Is Plasma at Risk of H1N1 Flu?

Individuals with immune disorders should not be concerned that their IG product has been tainted by infected plasma. According to FDA regulations, individuals who are not in good health are not suitable to donate blood, and blood establishments must defer these potential donors. In addition, the H1N1 virus is a large lipid-enveloped virus, and validation studies performed by product manufacturers have shown that viruses with similar characteristics are effectively

inactivated and/or removed by the manufacturing processes.⁴

Conclusion

While it is unknown at this point just how widespread the H1N1 flu will become, historically, many new strains of a flu virus have started relatively mildly in the spring, only to fizzle out later. On the other hand, other new flu viruses classified as pandemics also started mildly in the spring, and then returned with a vengeance in the fall and winter when viruses peak.

The World Health Organization, CDC and state agencies are gathering information about the H1N1 flu on a daily basis in an effort to assess how serious it is, minimize the spread of disease, and inform and educate the public. For now, the best advice for individuals with immune disorders is to protect themselves against this flu as they would any other. ■

References

1. Questions and Answers about the Influenza A(H1N2) Virus. Accessed at <http://cdc.gov/flu/about/h1n2qa.htm>.
2. Centers for Disease Control and Prevention. Prevention and Control of Influenza: Recommendations of the Advisory Committee on Immunization Practices (ACIP), 2007. *Morbidity and Mortality Weekly Report* Recommendations and Reports, July 13, 2007, 56(RR06);1-54.
3. Primary Immunodeficiency Association. Swine Flu — Your Questions Answered. Accessed at http://www.pia.org.uk/documents/PIAQandAonSwineFlu05May09_000.pdf.
4. Primaryimmune.org. 2009 H1N1 Flu Virus: Information about Newly Emerging 2009 H1N1 Influenza (Swine Flu) Virus and Blood Safety. Accessed at http://www.primaryimmune.org/admin_content/admin_files/FDA.pdf.

Nutrition Therapies for Autoimmune Conditions



While it is believed that many nutrition therapies will be helpful for those afflicted with autoimmune disease, separating the wheat from the chaff will help patients to understand what clinically is and isn't proven to work.

“Leave your drugs in the chemist’s pot if you can heal the patient with food.”

— Hippocrates

By Jessica Schulman, PhD, MPH, RD, CLE

Inflammation is a normal part of a healthy immune system. When the body identifies an injury or foreign material (such as a “bad” bug), it naturally releases messengers such as cytokines and eicosanoids that start a campaign to fight and conquer. The result is swelling or fever caused by microscopic soldiers (e.g., phagocytes, mast cells, eosinophils, basophils, antibodies and T-cells) engulfing, neutralizing or killing the foreign invader. While the inflammation can be a nuisance, it usually means the body is successfully solving a problem, and in a few days, it feels better.

For individuals with autoimmune diseases, this normal response is out of balance. The immune system misreads the situation, attacking invaders that are not there, or continuing to attack long after the invader has been defeated. In these cases, the body keeps releasing its weaponry, essentially attacking itself. The irony is a bitter one: The same processes that heal most people damage the bodies of those living with autoimmune and inflammatory diseases. For some individuals, this scenario is temporary but, for others, this dysregulation of immune responses may flare up regularly or continue over a period of time.

It is estimated that about 8 percent of the population (14.7 million to 23.5 million) is affected with autoimmune conditions, but they are especially prevalent among those living with immune irregularities.¹ For example, according to scientists at the Stanford University School of Medicine's Immunology Program, "Approximately 25 percent of subjects with CVID [common variable immune deficiency] suffer from autoimmune disease which could be the result of immune dysregulation."² These persistent and often debilitating conditions — including arthritis, celiac disease, ulcerative colitis, Crohn's disease, spondylarthropathy, thyroiditis and others — have profound effects on individuals, families and society: Children miss school and social activities, adults miss work and are less productive, medical costs skyrocket and lives are lost.

Although there are treatments for many of these diseases, there are few cures, so individuals and their caregivers often look to complementary therapies such as nutrition for relief. The Internet is full of self-appointed nutritionists describing specific foods that they promise will soften pain and improve clinical symptoms. For those suffering from autoimmune conditions, this advice offers hope, but, as is so often the case with promises that sound too good to be true, many of these effects have not been supported by research. In fact, few human studies demonstrate that autoimmune conditions can be effectively treated through

Few human studies demonstrate that autoimmune conditions can be effectively treated through the consumption of specific foods.

the consumption of specific foods or their concentrated extracts (also known as nutraceuticals). At the same time, those suffering from these conditions can improve their quality of life through optimal nutrition. Following is information that reviews and discriminates between nutrition therapies that are grounded in science and those that are still under investigation.

Eating a Balanced Diet to Reduce Inflammation

There is no single anti-inflammatory diet for everyone; a specialized diet that helps one person may be like poison for the next. Those who are hypersensitive to certain foods, such as peanuts, gluten, cow milk protein, etc., know to avoid them. In the absence of a known food allergy, or a specialized diet prescribed by a doctor, the best advice is to eat a varied diet of nutrient-dense foods, as described in the USDA dietary guidelines (mypyramid.gov/). This may sound obvious, but in fact, a varied and balanced diet may have specific benefits for individuals with autoimmune disorders. We are still learning about food components that modulate immune function. For example, only recently did we learn that fiber is a source of prebiotics, which feed "friendly" bacteria in the gut.³ Similarly, it is only in the last few years that research has proven that fats from meat sources and certain oils contribute to inflammation, whereas fats from foods such as fish reduce the signals in our body to attack. Eating a balanced diet ensures that we reap the benefits of what is known about healthy nutrition, as well as what we have yet to discover.

What does a balanced diet look like? It consists of brightly colored fruits, vegetables, legumes and potatoes. It also includes whole, fortified and fiber-rich grains such as brown rice, flaxseed and lentils, as tolerated, as well as lean meats, fish and low-fat dairy. It is important that foods are consumed only to meet the energy needs of an individual and that a healthful weight is maintained.

Overweight places extra stress on the body. Excess fat tissue, in particular, can generate certain compounds like hormones that may exacerbate autoimmune conditions. On the other hand, underweight can leave an individual more vulnerable to infections and slow recovery time. Questions regarding weight and individualized diet therapies can be directed to the American Dietetic Association at www.eatright.org or (800) 877-1600 and www.rdlink.com.

Antioxidants

There are hundreds of antioxidants that might affect inflammation or pain in joint disease, but as yet, little research justifies consuming therapeutic doses of any particular one.⁴ For example, although researchers have described the protective effects of green tea and red wine (polyphenol oxidants) in association with cancer and heart disease, limited information about the effects of these compounds on arthritis, inflammatory bowel disease (IBD) and other autoimmune conditions exists. A recent review of the literature concluded: "Until we have a better understanding of which — if any — dietary antioxidants are responsible for antiarthritic effects ... a daily intake of a variety of fresh vegetables and fruits, with their naturally occurring antioxidants, is a more rational approach to maintaining a healthy immune system than supplementation with nutraceuticals."⁴

Omega-3 Fish Oil

Over the last several decades, one of the biggest dietary changes in Western countries has been the increased consumption of linoleic acid (omega-6) through margarines and cooking oils.⁵ Omega-6 fatty acids are known to play a role in sensitization and the allergic response, and they contribute to inflammation and immunity. Researchers have suggested that the increased consumption of omega-6 fatty acids may account for the rise in autoimmune disease as well.⁶ To the extent that this is true, then consuming acids that work against the action of omega-6 fatty acids would have the potential to reduce inflammation. Nonsteroidal anti-inflammatory drugs like aspirin, ibuprofen and naproxen work in a similar way. Omega-3 fatty acids, like those found in fish oils, have received particular attention for their role in counteracting the effects of omega-6 fatty acids.⁶

Dr. Philip Calder, professor of nutritional immunology at the University of Southampton in the United Kingdom, and world renowned for his work on how fatty acids



(alpha-linolenic acid that is rich in EPA and DHA) or omega-3s from marine animals impact inflammation and immunity, says he was cautious about the use of foods or nutraceuticals for treating autoimmune conditions like arthritis and IBD. He warns that there is "real difficulty in translating studies and experimental models into clinical efficacy." With respect to omega-3s in particular, however, he says he was encouraged by research on healthy volunteers showing "that it is possible to influence aspects of inflammatory arthritis by administering fish-derived omega-3s orally."

Most of the clinical trials that Calder describes show benefits for people living with rheumatoid arthritis (RA).⁷ According to Calder, "The evidence is robust if you use a high enough dose ... from 2 to 4 grams." Evidence for IBD is much weaker than for RA, and Calder points out that, "If you look at other autoimmune conditions, like lupus or psoriasis, there probably aren't enough studies to come to a good enough conclusion about omega-3."

How does any of this information apply to those living with a suppressed immune system? Calder explains that, "This has been a big question which is not fully resolved ... and there is not really strong science in humans to give us a pointer." However, he suggests that those with immune dysfunction have little to lose from taking omega-3 supplements because, "Unless there is a nutrient deficiency, the effect of anything nutritional is not likely to be profound, unlike other pharmaceuticals that can wipe out a functioning system."

For individuals who think they might benefit from more omega-3s in their diet, it is first important to note that

fatty acids from fish are significantly more effective than those from plants. This is why the most common way of boosting omega-3 fatty acid consumption is through fish oil capsules. How do consumers know about the safety, purity and quality of fish oil supplements? They don't, says Calder, because there are so many brands available. Unfortunately, over-the-counter supplements are not adequately tested, and their safety may not be proven. Moreover, there are a number of reasons for some people to avoid fish oil, such as bleeding disorders or fish allergies. Therefore, safety issues should be reviewed before considering any supplements (www.nlm.nih.gov/medlineplus/druginfo/natural/patient-fishoil.html). In the U.S., the best that consumers can do is consult with their physicians, find out which brands were used in human clinical trials, and register with companies that conduct independent supplement testing (www.consumerlab.com). In addition, individuals should always talk with a qualified healthcare provider before starting any complementary therapy.

A balanced diet will further improve outcomes. Says Calder: "If you lower arachidonic acid by, let's say, eating a diet that is lower in omega-6s, and at the same time increasing the amount of omega-3s from fish oil, you can probably get a better effect than just using omega-3 supplements by themselves."⁸ (For more information on arthritis, Calder suggests the book *Nutrition and Arthritis* by Margaret Rayman.)

Probiotics

For people whose bodies have trouble regulating responses to invaders, it may sound strange to recommend consuming microbes. Yet, in recent years, a number of researchers have suggested that more "good" bacteria is exactly what is needed. Researchers have proposed that, as the urban environment has become altered (i.e., through the routine use of antibiotics, institutionalized healthcare, separation of people from farming, etc.), people are less likely to develop the healthy flora that help them

fend off harmful bugs. This leaves the gut vulnerable to acquiring pathogenic organisms and "superbugs." Or, as Calder puts it, "The immune system doesn't have friendly bacteria to play with ... so it starts playing with things that it shouldn't play with." The answer to this problem is not to be less clean, but to make sure that people have the opportunity to develop healthy flora and intestinal mucosa.

Probiotics are exactly that: therapeutic doses of "friendly" microbes such as *Lactobacillus rhamnosus* GG, *L. reuteri*, bifidobacteria, *Saccharomyces boulardii*, etc. These bacteria colonize the gut and modify the gut flora, offering a potential therapy in conditions associated with infections, gut-barrier dysfunction and autoimmune conditions.⁹ There are many different types of probiotics, and research is beginning to identify which ones are more or less effective for treating IBD. Some examples of probiotic foods include miso soup, some soft cheeses, yogurt products like kefir, sauerkraut and many pickles. It is worth noting that not all probiotics are considered safe and effective. For example, fragile patients or those with impaired T-cell response to candida may not do well with yeast-based probiotics.

It is important that foods are consumed only to meet the energy needs of an individual and that a healthful weight is maintained.

Preventing Malnutrition

In autoimmune diseases that target the gut, such as ulcerative colitis and Crohn's disease, there is a complex interaction between genetic and environmental factors such as nutrition. (A detailed article on celiac disease is available at www.igliving.com/web_files/d-j09_Celiac.pdf.) One of the biggest challenges is to prevent nutrient deficiencies, promote growth in children and protect bones, muscles and immune function.¹⁰ Physicians should pay special attention to preventing anemia by monitoring iron, B12 and folic acid status, and protecting bone by ensuring adequate calcium, magnesium and vitamin D intake. There is growing evidence to suggest an anti-inflammatory role and immune system regulator for vitamin D in Crohn's disease.¹¹ The role of nutritional therapy in the management

of adult Crohn's disease is not clear, but there is evidence for the use of an enteral diet among children. Researchers describe the potential anti-inflammatory effects of certain enteral diets on the gut mucosa. Consistent with current literature, they speculate that this may be related to particular fatty acids and/or components that alter the gut flora. Still, more bench and clinical research needs to be conducted.



Summary

Complementary nutrition therapies offer much promise for reducing the severity of certain autoimmune and inflammatory conditions. But, individuals need to be cautious about using ingredients that have been concentrated and purified for therapeutic purposes. More clinical trials need to be conducted before the public can identify the appropriate dosages and nutritional supplements for the treatment of autoimmune diseases. At the same time, individuals who claim to feel better after eating or avoiding certain foods should not be dismissed. As a leading physician and nutrition expert said, when talking about the accidental discovery of a way to keep milk safe for human consumption: "Casual observations, if carefully made, often prove to be more than incidental in importance!"¹²

Clinicians who are experienced in using nutrition therapies may advise patients on an individual basis. Likewise, patients using nutraceuticals, probiotics or specialized diets ought to seek counsel and supervision from their physician. A

reasonable scenario might be the combined use of nutritional and medical interventions to improve outcomes and quality of life. Even if lifestyle and dietary factors are proven effective in treating certain autoimmune conditions, these strategies will not likely be curative. In such cases, diet and supplements should be used judiciously and not as a substitute for medical intervention. Patients with severe autoimmune diseases or regulator T-cell dysfunction, for example, may require stem cell transplant. As Sophocles reminded us two millennia ago: "A wise doctor does not mutter incantations over a sore that needs the knife."

References

1. National Institutes of Health, The Autoimmune Diseases Coordinating Committee. *Progress in Autoimmune Disease*, 2005. Available at: <http://www3.niaid.nih.gov/topics/autoimmune/PDF/ADCCFinal.pdf>.
2. Yu, GP, Chiang, D, Song, SJ, et al. Regulatory T cell dysfunction in subjects with common variable immunodeficiency complicated by autoimmune disease. *Clin Immunol*, 2009 [Epub ahead of print].
3. Lomax, A, Calder, PC. Prebiotics, immune function, infection and inflammation: A review of the evidence. *British J of Nutr*, 2008; 101:pp.633-658.
4. Pattison, DJ, and Winyard, PG. Dietary antioxidants in inflammatory arthritis: Do they have any role in etiology or therapy? *Nature Clin Prac Rheumatology*, 2008; 4:pp.590-596.
5. Shoda, R, Matsueda, K, Yamato, S, and Umeda, N. Epidemiologic analysis of Crohn disease in Japan: Increased dietary intake of n-6 polyunsaturated fatty acids and animal protein relates to the increased incidence of Crohn disease in Japan. *Am J Clin Nutr*, 1996; 63(5):pp.741-745.
6. Calder, PC. Personal communication. Professor of Nutritional Immunology at the University of Southampton, UK. March 2009.
7. Calder, PC. N-3 Polyunsaturated fatty acids, inflammation, and inflammatory diseases. *Am J of Clin Nutr*, 2006; 83(suppl):pp.1505S-1519S.
8. Adam, O, Beringer, C, Kless, T, et al. Anti-inflammatory effects of a low arachidonic acid diet and fish oil in patients with rheumatoid arthritis. *Rheumatol Int*, 2003; 23:pp.27-36.
9. Chow, J, and Mazmanian, SK. Getting the bugs out of the immune system: Do bacterial microbiota "fix" intestinal T cell responses? *Cell Host and Microbe*, 2009; 5:pp.8-12.
10. O'Sullivan, M, and O'Morain, C. Nutrition in inflammatory bowel disease. *Best Practice Research*, 2006; 20(3):pp.561-573.
11. O'Sullivan, M. Nutrition and autoimmune disease; nutrition in Crohn's disease. *Proceedings of the Nutrition Society*, 2009; pp.1-8.
12. Hansen, AE. Essential fatty acids and infant nutrition. *Pediatrics*, 1958; 21:494-501.

Editor's Note: This article is intended for general information only. Individuals with medical conditions should consult a physician to determine what eating pattern or supplements are right for them.

JESSICA SCHULMAN, PhD, MPH, RD, CLE, is a credentialed dietitian and lactation educator, holds a doctorate in health behavior, and is the author of the book, *Nutrition in Sickness and in Health*.

Helping solve the acute problems of
availability, affordability and **safety**
in chronic care



NuFACTOR is the specialty pharmacy subsidiary of FFF Enterprises, the nation's most trusted distributor of plasma products, vaccines and other biopharmaceuticals. Count on NuFACTOR for antihemophilic factor, immune globulin and other special injectables.

NuFACTOR, FFF's specialty pharmacy, is your reliable source for home infusion and critical-care products:

- IVIG & SCIG
- Antihemophilic factor
- Growth hormone therapies
- Multiple sclerosis therapies
- Hepatitis therapies
- Other chronic injectable and infusion therapies



NuFACTOR has earned the Joint Commission Gold Seal of Approval

National Reach—Local Touch | 24/7 Emergency Ordering | Bilingual Representatives

Call: (800) 323-6832

Fax: (877) 432-6258

www.NuFACTOR.com

Antibiotics: Avoiding Interactions

By Amy Ehlers, BS, PharmD, BCPS

According to the Food and Drug Administration (FDA), there were more than 480,000 adverse events associated with drugs and therapeutic biological products reported by consumers, healthcare providers and drug manufacturers in 2007. Of these, nearly half a million adverse events, or more than 270,000, were associated with a serious outcome, such as hospitalization or death. While this number may appear high, it represents only a fraction of the nearly 3.5 billion prescriptions that were filled in retail pharmacies in 2007.

The single, largest group of medications, antibiotics, can have side effects and interactions that can range from mild and inconvenient, to serious and potentially life-threatening. How can patients avoid becoming one of these adverse event statistics?

Use of Antibiotics

Patients should avoid taking antibiotics unless absolutely necessary. This may be much easier said than done for those with an immune deficiency. However, ensuring that patients do not self treat unless directed by a physician is the most important first step. Antibiotics are effective only against infections caused by bacteria and should not be used for viral illness such as influenza, colds and non-bacterial sore throats.

Following directions is also important. There is a misconception that if a little medicine works, a lot must be better. Patients may be tempted to increase the dose or frequency of their medication, because they are "really sick" compared to last time. But, making this decision without consulting a physician can have



serious consequences. It can cause kidney or liver damage or other potentially permanent effects.

With each overuse or misuse of antibiotics, the risk of antibiotic resistance increases. Bacteria are able to quickly mutate in an attempt to survive the hostile environment created by the antibiotic. Over time, the bacteria adapt in



*With each overuse
or misuse of antibiotics,
the risk of antibiotic
resistance increases.*

such a way that they become harder to kill and have the potential to cause more serious infections that are more difficult and costlier to cure. These antibiotic-resistant bacteria then have the ability to be spread to others.

One of these bacteria, *Clostridium difficile* (often referred to as *C. difficile* or *C. diff*), is also a potential risk with antibiotic use. *Clostridium difficile* naturally occurs in the large intestine. With broad-spectrum, high-dose or long-term antibiotic use, especially in older adults, the other normal bacteria in the gut die off, allowing the *C. difficile* to overgrow and produce toxins. These toxins cause swelling and irritation of the large intestine that manifests as watery diarrhea (at least three episodes a day for two consecutive days), fever, loss of appetite, nausea and abdominal pain/tenderness. In more severe cases, *C. difficile* can cause pseudomembranous colitis, a severe inflammation of the colon with blood and pus in stools, which can cause death. This infection can be treated with oral metronidazole or oral vancomycin. However, like other bacteria, resistant strains of the *C. difficile* bacteria have been seen, which have caused conventional treatments to be less effective.

Antibiotics and Drug Interactions

Drug interactions are a concern with antibiotic use. There are several categories of drug interactions: drug-drug, drug-food and drug-nutrient.

Drug-drug interactions are the most likely to cause more serious events. Most of these interactions occur due to a change in one of the drug's levels caused by a change in metabolism of one the drugs. The greater the change in drug concentration or the more narrow the therapeutic window, the more likely or severe a drug interaction will occur.

A well-documented drug interaction is between oral contraceptives and antibiotics. An increase in the clearance of the oral contraceptive estrogen can decrease its effectiveness. Patients should discuss appropriate alternatives with either their physician or pharmacist.

Patients taking the drug warfarin (Coumadin) should also be aware of the potential for a change in their bleeding duration. Warfarin doses may need to be adjusted while on an antibiotic, and then changed again once antibiotic therapy is completed.

The heart medication digoxin (Lanoxin) can be problematic when taken with several antibiotics. Digoxin has a narrow line between effectiveness and toxicity, so when taken with antibiotics such as clarithromycin (Biaxin) or azithromycin (Zithromax), the level of digoxin may increase, causing some of its toxic side effects.

Antibiotics can have interactions not only with other drugs, but food as well. It is important to know if there are any restrictions when taking antibiotics in relation to meals. Most antibiotics can be taken independent of meals and snacks, but that is not always the case. For example, amoxicillin (Amoxil) is best taken on an empty stomach, which is usually defined as one hour before or two hours after a meal. If taken with food, the effectiveness of the antibiotic is reduced and may be the equivalent of throwing the dose in the trash.

The type of foods eaten with antibiotics may also be of concern. For instance, grapefruit juice has been shown to affect the metabolism of a large group of drugs, including some antibiotics. Patients who tend to consume large amounts of whole grapefruit or juice should inform their physician and pharmacist.

Medications in the tetracycline (doxycycline) and fluoro-

Table 1. Antibiotics and Their Common Uses

Antibiotic Class	Generic Name (Brand Name)	Common Uses
Penicillins	Penicillin V (Pen V K) Amoxicillin (Amoxil) Amoxicillin/clavulanic acid (Augmentin)	Skin, urinary tract, dental, ear infections
Cephalosporins	Cephalexin (Keflex) Cefaclor (Ceclor) Cefuroxime (Ceftin)	Pneumonia, upper respiratory, skin, ear, dental infections
Macrolides	Erythromycin (Ery tab) Azithromycin (Zithromax) Clarithromycin (Biaxin)	Respiratory, gastrointestinal, soft tissue, genital infections
Fluoroquinolones	Ciprofloxacin (Cipro) Levofloxacin (Levaquin) Moxifloxacin (Avelox)	Respiratory, skin, urinary tract infections
Sulfas	Sulfamethoxazole/Trimethoprim (Bactrim DS) Sulfisoxazole (Gantrisin)	Urinary tract, skin, ear infections, chronic bronchitis exacerbations
Tetracyclines	Tetracycline (Achromycin) Doxycycline (Vibramycin) Minocycline (Minocin)	Respiratory infections, acne, Lyme disease

quinolone (ciprofloxacin) classes should not be taken with calcium-, magnesium-, iron- or zinc-containing foods or dietary supplements one hour before or two hours after. The drugs will bind with these elements rendering them ineffective. Calcium, magnesium, zinc and iron can be found in foods and dietary supplements, such as multivitamins, as well as over-the-counter medications, such as antacids.

Herbal medications also have the potential to interact with antibiotics. St. John's wort, an herbal product often used for depression, can increase the photosensitivity in fluoroquinolone, tetracycline or sulfa antibiotics. Green tea extracts, when taken with fluoroquinolones, can decrease the clearance of the caffeine and its derivatives found in the green tea. This may cause an increase of classic caffeine symptoms such as nervousness, insomnia and heart palpitations.

It should be noted that the herbal and natural products industry is not regulated by the FDA and, therefore, is not held to the same manufacturing standards and practices as prescription and over-the-counter medications. This is not to say that all herbal and natural products are unsafe and should not be used. What this means is that the review process concerning appropriate doses and dosage forms and the study of side effects and interactions are not required and, therefore, there is no oversight to ensure

the products are safe and effective. As a precautionary measure, patients should read all information contained on a product's label and packaging, and discuss using the product with their physician or pharmacist.

Mixing alcohol and antibiotics can have different effects depending on the drug. Alcohol can cause side effects such as drowsiness, stomach upset and dizziness. When alcohol is consumed with antibiotics, the same outcomes can occur and the effect can be intensified. When the drug metronidazole (Flagyl) is taken with alcohol, a severe reaction, called a disulfiram reaction, can occur. This reaction will cause nausea, vomiting, flushing, headache, rapid heart rate and shortness of breath. Patients should be aware that there may be alcohol in over-the-counter cold and cough medications, as well as mouthwash.

As a rule of thumb, patients should always protect themselves when out in the sun. This is especially important when taking fluoroquinolones, tetracycline or sulfa antibiotics, as these types of antibiotics can cause photosensitivity, which can cause sunburns despite the use of sunscreen.

Antibiotics and Drug Allergies

Drug allergies are another common challenge with medications, but especially with antibiotics. An allergic response is defined as a hypersensitive immune reaction to

a substance that normally is harmless or would not cause an immune response in most people. There are two main types of allergic reactions: IgE mediated and T cell mediated. Reactions that are IgE mediated typically occur within one to two hours of exposure and may include anaphylaxis and/or anaphylaxis-related symptoms, such as bronchospasm (difficulty breathing), angioedema (swelling of the face, mouth and throat) and urticaria (hives). These reactions are serious and potentially life-threatening, and require immediate medical attention. T cell mediated reactions are usually delayed reactions occurring anywhere from six hours to weeks following exposure, and they are commonly expressed as skin symptoms, such as a rash. These reactions can be resolved on their own or with antihistamine or steroid treatment.

If a patient suspects an allergic reaction to a medication, they should contact their physician to determine the next steps to take, and provide them the opportunity to see the reaction firsthand. Once an allergic reaction is confirmed, the drug and reaction should be noted in the patient's medical record and consistently noted when seeing any healthcare provider.

It is not uncommon for patients to report allergies to medications that are actually sensitivities to, or known side effects of, the medications. Many side effects of antibiotics are not life-threatening, but they can make life miserable. Patients may report a sensitivity or side effect as an allergy based on their level of tolerance to the specific side effect.

For example, diarrhea is fairly common with the oral antibiotic Augmentin, which is in the penicillin family. Patient A may describe the event as a less-than-pleasant experience, but tolerable, and will be able to complete the entire course of therapy. If Patient A were to be prescribed Augmentin again, they may ask for an alternative if possible, but would not describe themselves as being allergic to either Augmentin or penicillin. Patient B may describe the same event as the worst experience ever and stop taking the medication after the first few days.

If Patient B were prescribed Augmentin again, they will state that they are allergic to it and can never take it again. Their physician marks the medical record as allergic to Augmentin.

This may never be an issue. But, what happens if Patient B is hospitalized with a serious staph infection and the treating physician wants to use nafcillin, a penicillin derivative? If Patient B merely states that they are allergic to penicillin and does not or is unable to disclose that the reaction was diarrhea, the physician will be forced to pick another class of antibiotics. The alternate choice of antibiotic may require a longer duration of therapy, have an increased potential for side effects or be more expensive than the original antibiotic preferred by the physician.

It is not uncommon for patients to report allergies to medications that are actually sensitivities to or known side effects of the medications.

Taking Control of Antibiotic Use

The best advice when it comes to safely using not only antibiotics, but any medications, is to have open, constant and thorough communication with all members of your healthcare team. Patients should keep lists of all prescriptions, over-the-counter, vitamins and herbal products taken regularly,

including the date started, strength, dose and frequency of administration. This list should be updated regularly and given to any provider who is not aware of the changes to help avoid problems before they occur. Medications should always be taken as prescribed by the physician, and patient counseling information provided by the pharmacist should always be followed. If something is unclear, patients should not be afraid to ask questions or to ask for something to be repeated or further clarified. Ultimately, patients are responsible for their own health and well-being and should take an active role in trying to achieve that goal. ■

AMY EHLERS, BS, PharmD, BCPS, is the director of pharmacy at NuFACTOR Specialty Pharmacy. She has a bachelor's and doctorate degree in pharmacy, and is board certified in pharmacotherapy.



Subcutaneous IG Therapy: An Alternative

The success of four primary immune deficiency patients who switched from IVIG to SCIG treatment shows that this new form of IG therapy may, in some situations, be a beneficial alternative for some individuals.

By Mark R. Stein, MD

Primarily immune deficiency (PID) encompasses more than 150 inherited disorders that impair different components of the immune system.¹ An estimated one in 1,200 individuals in the United States, or approximately 250,000 people, have been diagnosed with some form of PID.² The disorders are characterized by recurrent or unusual infections that rarely affect healthy people.³ Antibody deficiencies are the most common forms of PID^{2,4} and are usually associated with upper respiratory tract infections, most notably sinusitis and otitis media.² Treatment options for PID include intravenous or subcutaneous immunoglobulin (IG) replacement therapy, prophylactic treatment with antibiotics and immunizations, and, in some cases, gene therapy or bone marrow transplantation.⁵

Immunoglobulin replacement therapy is the cornerstone of treatment for many patients with PID, particularly for those with antibody deficiencies,^{5,6} and intravenous immunoglobulin (IVIG) is the most popular form of IG therapy in the United States.^{5,6} However, IVIG often requires administration at an office, infusion clinic or hospital. Most patients experience decreased infections, minimal side effects and have minimal inconvenience with IVIG. Yet, some patients find their IVIG therapy may be associated with certain systemic reactions, such as headache, chills, flushing, low back pain, nausea and, in rare instances, thromboembolic events.^{7,8} Some patients experience a feeling of fatigue or notice an increased incidence of infections in the week prior to their IVIG infusion.

An alternative to IVIG is subcutaneous immunoglobulin (SCIG) therapy.^{9,10} SCIG allows patients to self-administer infusions at home, and may be especially appropriate for people with PID whose veins are difficult to access, who cannot tolerate the side effects of IVIG, or who prefer the independence and flexibility of at-home administration. The following case studies describe how four people successfully switched from IVIG to SCIG therapy.

Case 1

Eddie is an 8-year-old boy who was diagnosed at age 1 with X-linked agammaglobulinemia (XLA) and started on monthly IVIG therapy. However, even with IVIG treatments, Eddie continued to suffer from frequent sinus and bronchial infections. Thus, his parents were concerned about Eddie potentially being around sick children at school. Getting treatment for Eddie required one parent to take off work once every three weeks for the eight-hour roundtrip to Eddie's infusion appointment. Eddie's parents, Amanda and John, took turns bringing him for the infusions, but the time away from work was still a strain for them. In addition, the infusion schedule and other appointments stopped Eddie and his brother from participating in certain extracurricular activities they might otherwise have enjoyed.

Further, Eddie was having difficulty maintaining minimally protective serum IG levels above 500 mg/dL. A review of his medical records revealed that he had experienced one serious bacterial infection and six sinus or bronchial infections in each of the two years since he had started on IVIG. Despite altering his dosing regimen from every four weeks to every three weeks and increasing the dose, infections persisted. Eddie's parents continued to express concern with their child's potential exposure at school, and their infusion scheduling difficulties continued to cause discontent. Eventually, the family decided that home-based therapy for Eddie would be more appropriate for their busy schedules. Eddie's immunologist suggested SCIG.

Amanda and John quickly learned SCIG infusion techniques and are now very pleased with their ability to administer Eddie's IG therapy at home on their own schedule. They don't need to take time off work, and Eddie and his brother are able to participate in additional extracurricular activities. At first, Eddie experienced mild to moderate redness and swelling at the site of subcutaneous infusion, but this has decreased substantially with subsequent infusions. His IgG level increased, and his rate of infections decreased with his change of therapy.

Case 2

Catherine is a 45-year-old international consultant with common variable immunodeficiency (CVID) who has received monthly IVIG therapy for eight years. She responded well to therapy, but her extensive, unpredictable travel schedule conflicted with her monthly IVIG infusions. Her infusions generally took four to six hours and were tolerable only when administered at a slower than normal rate. Further, the headaches and nausea that accompanied the infusions sometimes forced her to cancel important meetings.

Catherine's physician was concerned about the side effects of IVIG, and the possibility that her business travel and professional demands would interfere with her monthly infusions. He noted that she had either missed or rescheduled infusions, extending the time between treatments. Typically after missed treatments, she experienced repeated upper respiratory infections. So, at her physician's recommendation, Catherine switched to SCIG. She adapted quickly and has been very happy with her ability to infuse at home and on business trips. And, she is pleased that she can easily transport her infusion therapy products on business trips. Catherine has told her friends that she is less stressed about traveling because her trips no longer conflict with her IG therapy. She has not experienced systemic adverse events, and while she has experienced mild to moderate infusion site reactions, they decrease substantially after 24 hours, and have not disrupted her work schedule. With regular home therapy, she noticed a significant reduction in her rate of infections.

SCIG therapy offers an alternate route of administration for patients with poor venous access.

Vivaglobin SCIG Treatment

Vivaglobin is the first and only 16 percent subcutaneous immunoglobulin therapy approved by the Food and Drug Administration for the treatment of primary immunodeficiency patients in the United States. Weekly subcutaneous therapy with Vivaglobin helps provide consistent protection against infections by maintaining consistent blood levels of immunoglobulin.

Case 3

Margaret, a 77-year-old woman, was diagnosed with CVID nine years ago and began receiving monthly IVIG therapy. She has been pleased with her overall health since starting IVIG therapy. However, since she does not drive, she incurred additional cost for transportation to and from the infusion clinic. Her IVIG treatments caused frequent headaches and resulted in pain in both arms due to her “poor” veins, making it difficult for her to take care of herself at home. Although she received medication prior to infusions and the infusion rate was slowed, Margaret continued to experience adverse events. She was unhappy with the lengthy infusion time, side effects and travel costs.

Margaret has limited peripheral vascular access after episodes of inflammation of her veins (phlebitis). Because she is often mildly dehydrated, her veins tend to collapse upon venipuncture. She was recently diagnosed with type 2 diabetes, and is now taking an oral antidiabetic drug and following a restricted diet. Because of the adverse reactions, Margaret required professional observation during infusions. After complaining to her physician about the adverse reactions, the difficulty of accessing a vein for injection and the duration of IVIG therapy, Margaret learned about SCIG.

Margaret has not experienced any systemic adverse events with SCIG. She has reported mild itching, redness and some swelling at the injection site, but these side effects decrease substantially within a day after the infusion. Margaret no longer requires professional observation of her therapy and is pleased with her ability to self-infuse at home on her own schedule. Because she is no longer distracted by the side effects she experienced with IVIG therapy, Margaret has been able to focus on managing her diabetes.

Case 4

Daniel is a 32-year-old building tradesman with CVID who received monthly IVIG therapy for three years. Since his early 20s, he has suffered from increased frequent and unusual infections, including pneumonia. While IVIG therapy reduced Daniel’s recurrent bacterial infections, the therapy also caused consistent side effects, including headaches, chills, fever and severe nausea and diarrhea. His monthly IVIG therapy required six or more hours to infuse, plus an additional day of recovery. Because he is a non-union tradesman, Daniel does not receive paid days off. Thus, his lost wages and the out-of-pocket costs for treatment were both a financial burden for his family.

Daniel’s immunologist tried to reduce the systemic adverse events by switching Daniel to an IVIG product with a low IgA content. However, the reactions persisted. Because of these problems, Daniel decided to try SCIG.

Daniel adapted to self administration in one month and is very satisfied with SCIG. He has not experienced systemic adverse events. The injection site reactions are relatively mild and almost disappear after one day. Daniel is now able to maintain a full work schedule.



Summary

As these cases illustrate, SCIG therapy, which is administered subcutaneously, offers the convenience of in-home administration and may benefit patients who face transportation challenges or who have a busy lifestyle. SCIG therapy carries a lower risk of systemic side effects for some patients than does IVIG therapy.^{8,11} Finally, SCIG therapy offers an alternate route of administration for patients with poor venous access, a condition that may be particularly problematic for young children and elderly individuals. The above cases describe patients with ideal profiles for moving to SCIG therapy. However, it should be noted that SCIG is not appropriate for all patients, and IVIG remains an effective and well-tolerated alternative for many patients with PID. The choice to infuse intravenously or subcutaneously is personal. There are many factors that may lead the patient or physician to favor one or the other, and these factors should be carefully reviewed by the patient and physician together. At times, a patient will start one form of therapy and switch to the other based on side effects or inconvenience. ■

References

1. Bonilla, FA, Bernstein, IL, Khan, DA, et al. American Academy of Allergy, Asthma and Immunology; American College of Allergy, Asthma and Immunology; Joint Council of Allergy, Asthma and Immunology. Practice parameter for the diagnosis and management of primary immunodeficiency. *Ann Allergy Asthma Immunol*. 2005, 94(Suppl 1):S1-S63.
2. Boyle, JM, Buckley, RH Population prevalence of diagnosed primary immunodeficiency diseases in the United States. *J Clin Immunol*. 2007, 27:497-502.
3. Slatter, MA, Gennery, AR. Clinical immunology review series: an approach to the patient with recurrent infections in childhood. *Clin Exp Immunol*. 2008, 152:389-96.
4. Geha, RS, Notarangelo, LD, Casanova, JL, et al., for the International Union of Immunological Societies Primary Immunodeficiency Diseases Classification Committee. Primary immunodeficiency diseases: an update from the International Union of Immunological Societies Primary Immunodeficiency Diseases Classification Committee. *J Allergy Clin Immunol*. 2007, 120:776-794.
5. Immune Deficiency Foundation. Primary immune deficiency diseases in America: 2002. The second national survey of patients. 2002. Available at: [http://www.primaryimmune.org/publications/surveys/second_national_survey_of_patients_\(2002\).pdf](http://www.primaryimmune.org/publications/surveys/second_national_survey_of_patients_(2002).pdf). Accessed October 6, 2008.
6. Immune Deficiency Foundation. Diagnostic and clinical care guidelines for primary immunodeficiency diseases. 2006. Available at: http://www.primaryimmune.org/publications/book_diag/IDF_Diagnostic_and_Clinical_Care_Guidelines-Final.pdf. Accessed October 6, 2008.
7. Roifman, CM, Berger, M, Notarangelo, LD. Management of primary antibody deficiency with replacement therapy: summary of guidelines. *Immunol Allergy Clin North Am*. 2008, 28:875-6.
8. Misbah, SA, Chapel, HM. Adverse effects of intravenous immunoglobulin. *Drug Saf*. 1993, 9:254-262.
9. Davé, S, Hagan, J. Myocardial infarction during intravenous immunoglobulin infusion in a 65-year-old man with common variable immunodeficiency and subsequent successful repeated administration. *Ann Allergy Asthma Immunol*. 2007, 99:567-570.
10. Vivaglobin [package insert]. Kankakee, IL: CSL Behring LLC, 2007.
11. Berger, M. Subcutaneous administration of IgG. *Immunol Allergy Clin North Am*. 2008, 28:779-802.

Types of PID Described in Case Studies.^{1,4}

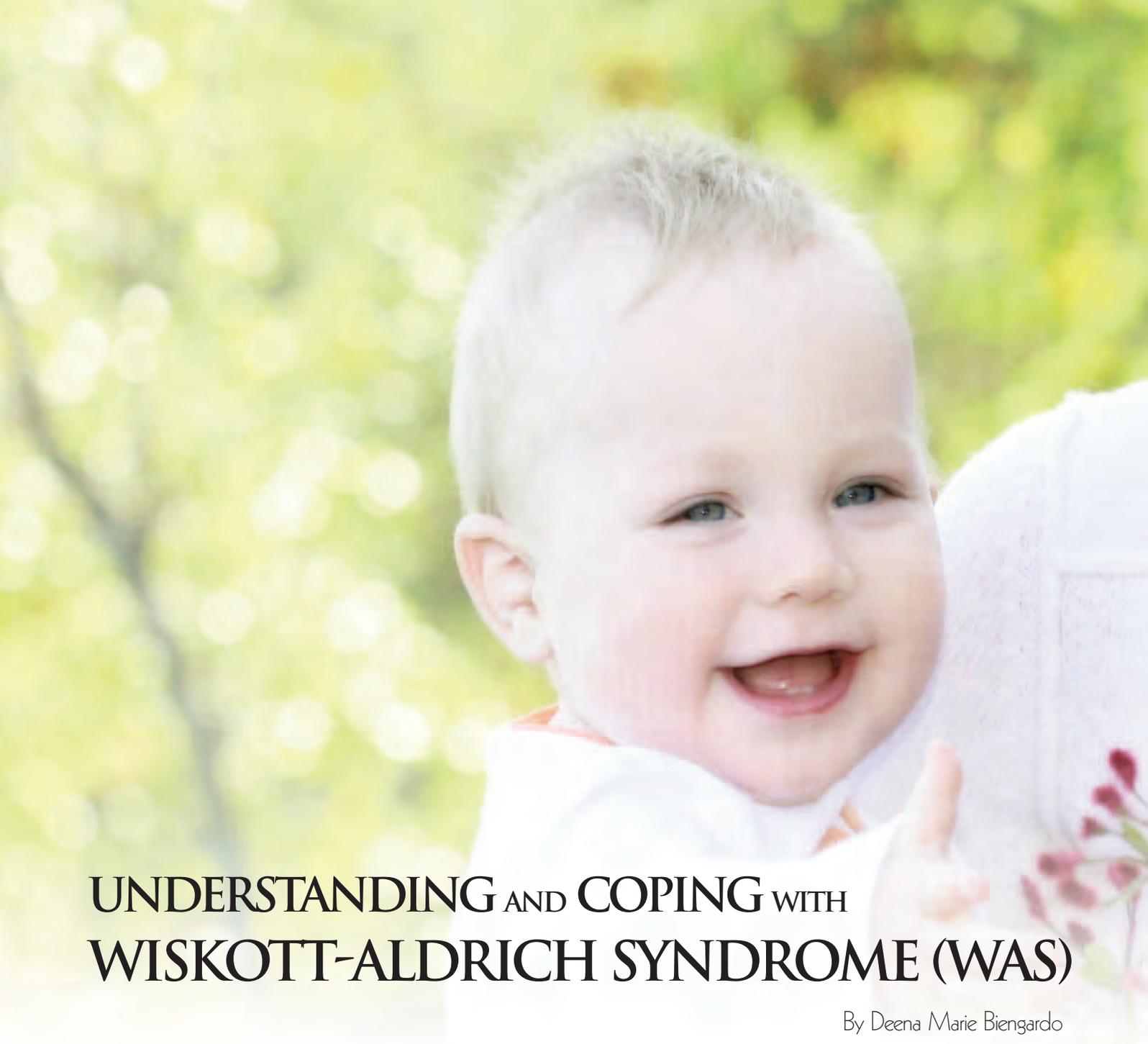
The four people discussed in the case studies in this article are affected by two of the more common types of PID. Following are brief descriptions of each.

Common variable immune deficiency. This antibody deficiency typically presents with recurrent sinopulmonary infections with encapsulated or atypical bacteria. Laboratory results show a reduction in one or more classes of immunoglobulins (e.g., IgA, IgG, IgM) and an inability to produce sufficient antibodies in response to pathogen exposure. B cells (the white blood cells that play an important role in the antibody-mediated immune response) may also be reduced.

Agammaglobulinemia. This is an antibody deficiency that usually presents with recurrent sinopulmonary infections (particularly otitis media, sinusitis and pneumonia) in the first two years of life. The defining laboratory features are reduced or absent B cells, resulting in an almost total lack of immunoglobulins (antibodies) in the blood.

MARK R. STEIN, MD, is in private practice at the Allergy Associates of the Palm Beaches in North Palm Beach, Fla. He is an investigator of IG products, including the Vivaglobin and Privigen studies for CSL Behring, and has also investigated IG products for Baxter, Octapharma, Grifols, Telecris and others.

Editor's Note: This article presents successful case studies of SCIG. However, IG Living magazine does not endorse any particular method or product. Those decisions should be made by the individual patient in consult with his/her physician.



UNDERSTANDING AND COPING WITH WISKOTT-ALDRICH SYNDROME (WAS)

By Deena Marie Biengardo

Patients with this rare disease and their families now have renewed hope of locating information and a support network to help them cope and survive.

Wiskott-Aldrich syndrome (WAS) is a rare, devastating disease that occurs in only four out of every one million live male births — which means only approximately 500 young men in the United States are afflicted with the disease. Because it is so rare, there is very little awareness, and diagnoses and information are hard to come by. But, with the creation of a new website, WAS patients now have a place to turn to for information and support.



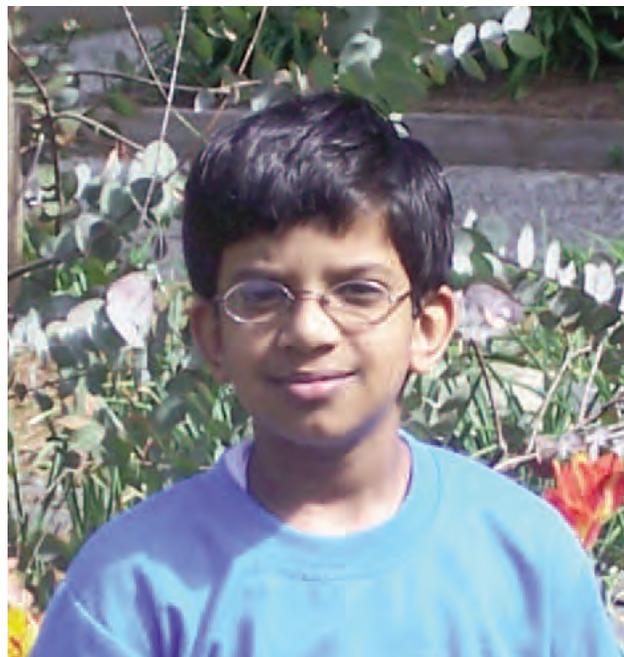
What Is WAS?

WAS is an immune deficiency disorder caused when not enough immunoglobulin is produced by the body. WAS patients suffer from low numbers of blood platelets that are small and do not function properly. The disorder is associated with a defective gene on the X (female) chromosome called the WAS gene. Females tend to be carriers of the gene, while males with the gene develop symptoms.

While WAS is generally symptomatic in children, individuals of all ethnic backgrounds in all geographic regions can be affected by it.

What Are the Symptoms of WAS?

Symptoms experienced by WAS patients include recurrent serious infections such as pneumonia, meningitis and sepsis; bloody diarrhea; prolonged bleeding; and unusual



Sumathi Iyengar, a pediatrician who developed a website for WAS patients and their families, has a son who was diagnosed with WAS at 1 year of age.

bruising. Additionally, patients have a genetic tendency to develop common allergic diseases such as eczema (itchy red or purple spots) caused by minor hemorrhage, and they are at significantly higher risk for developing autoimmune diseases and malignancies, such as lymphoma and leukemia.

How Is WAS Diagnosed?

WAS is diagnosed based on a blood film and low immunoglobulin levels. Often, leukemia is first suspected because of low platelets and serious, recurrent infections. Decreased levels of the WAS protein and confirmation of a causative mutation provide the most definitive diagnosis. However, there are different levels of mutation that are not only difficult to diagnose but also complicated to treat.

At the time of diagnosis, the patient may not demonstrate all of the typical WAS symptoms. The disease can present itself at varied levels of severity. A milder form of WAS is XLT (X-linked thrombocytopenia), where the patient presents mostly with a low platelet count. Another milder form of WAS is XLN (X-linked neutropenia), where the patient presents mostly with a low neutrophil count. Patients with XLT are often considered ITP (immune thrombocytopenic purpura), which means they have a low platelet count for no known cause. According

to Dr. Hans Ochs of Seattle Children's Research Institute, a physician with experience will diagnose a classic case of WAS within the first few months of life. Inexperienced physicians, on the other hand, often

WAS Treatment and Transplant Centers

Patients with WAS should be able to find assistance at most large Children's Hospitals. According to Dr. Hans Ochs, the best places to seek treatment are where stem cell transplants can be performed. In the West, transplants can be performed in Vancouver, B.C., Seattle, Portland, San Francisco and at the University of California, Los Angeles, and the Children's Hospital in Los Angeles. In the middle states, transplants can be performed in Denver, Dallas, Houston, Chicago (Northwestern University), St. Louis, Cincinnati, Minneapolis and New Orleans. In the East, they can be performed in Boston, New York, Washington, D.C., Duke University in North Carolina, Emory University in Atlanta, Ga., and Birmingham, Ala. In Canada, Sick Children centers in Toronto, Ont., can provide help to WAS patients.

WAS is diagnosed based on a blood film and low immunoglobulin levels.

make incorrect diagnoses. Therefore, many patients are not diagnosed as having a mutation of the Wiskott-Aldrich protein for years, and some patients are never diagnosed.

How Is WAS Treated?

Because WAS is primarily a disorder of the blood-forming tissues, a hematopoietic (blood-forming) stem cell transplant done through cord blood or a bone marrow transplant offers the only hope for a cure. So far, with stem cell transplantation, the life expectancy of a WAS patient is normal. Transplant is not always recommended, however. Symptomatic treatment can be provided to patients with milder forms of WAS, and with this, their average life expectancy is 15 to 30 years. Without any treatment, a patient's life expectancy is very short.

Symptomatic treatments for patients suffering from WAS are limited. Often, children wear a helmet to protect them in case they fall and bump their heads. This is meant to protect their brain from an injury that could cause a bleed. For severely low platelet counts and serious bleeds, patients may require platelet transfusions. A controversial treatment is splenectomy, or removal of the spleen. Splenectomy can raise platelet counts, but it is reserved for patients who are not transplant candidates, and it is currently not recommended unless the patient is having serious bleeding problems. Patients who undergo splenectomy have to be on prophylactic antibiotics every day afterward to prevent sepsis and other life-threatening infections. Anemic patients may even require iron supplementation or a blood transfusion. Intravenous immunoglobulin (IVIG), given to boost the immune system, is another option for patients with frequent infections.

Information and Support for WAS

Dealing with a diagnosis of WAS is devastating for families. It is especially perplexing to attempt to navigate through the maze of doctors, medications and new terminologies. So, a new website designed to bring the WAS community — patients, doctors and families — together may help to improve understanding, provide support and spur significant improvements in the care and cure of this disease.

Developed by Sumathi Iyengar, a pediatrician whose son was diagnosed with WAS at 1 year of age, the site includes a number of sections. The "find a doctor" feature allows patients to find local doctors who are capable of treating WAS, as well as other experts in the field. Doctors' contact information is listed, and links to their websites are provided. A "resources" page has links to medical literature, immunodeficiency foundations, and financial and transplant resources. And, a "how to cope" section provides information for families to better deal with the emotional aspects of dealing with this disease. Last, a link to a support forum where families can connect, exchange experiences and support one another is provided.

Raising Awareness of WAS

Because WAS affects a very small number of people, it has received little attention. Raising awareness about WAS among physicians, patients and their families will help to pave the way for early diagnosis, more research in the field and more funding. ■

WAS Resources

To access the Wiskott-Aldrich website, visit sites.google.com/site/athreyi
(Note: The WAS site is under construction and will be accessible in fall 2009.)

To access the WAS support forum, visit www.primaryimmune.org/forum/forum_intro.htm

DEENA MARIE BIENGARDO is a writer who lives in New York and is currently pursuing a degree in cultural studies.

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.



Joanne Pease is the mother of three sons — Curtis, 25, Jeff, 23, and Mitchell, 19 — who have X-linked agammaglobulinemia (XLA). This is a rare immunodeficiency that occurs in about one in 250,000 males. Females carry the gene but have no clinical manifestations. Two-thirds of cases are familial. One-third are believed to arise from new mutations. Typically, infections begin at about 6 months, after the antibodies that infants received from their mothers have been used up.

Shirley | When were your children diagnosed, and what role did you play in that diagnosis?

Joanne | My eldest, who was sick much of the time as an infant, was diagnosed when he was 2 years 3 months. At 15 months, he had a mumps vaccine and then he contracted mumps. After swimming in

the pool in summer, he got pneumonia. I kept taking him to the doctor again and again. The doctor was stumped, so he sent me to Children's Hospital, where he was diagnosed with XLA and started treatment with IG.

Jeff was a different story. I was concerned about him and kept bringing my concerns up to the doctor, but we were told we would not know if he had the condition until he was 1 year old. After Jeff had his polio vaccine, he stopped walking and standing, and moaned all the time. While I was convinced he had polio, the doctor told me to get over it, because no one gets that now. Since I was convinced there was something wrong, I took him to the emergency room at Children's Hospital where a very thorough doctor ordered a spinal tap, and Jeff was diagnosed with polio. He was immediately placed in isolation, and public health officials were notified. He was in the hospital for six days and was diagnosed with XLA. Since then, he has had 13 corrective orthopedic surgeries on his right leg, and he won't drive because he is not sure he will always be able to brake as needed.

Mitchell, my youngest, was tested and diagnosed by 7 months.

Shirley | Were there any red flags that stand out now?

Joanne | When Curtis was vaccinated with the mumps vaccine, he got mumps, which prompted me to ask the doctor, "What is the point of having kids vaccinated if they still get the mumps?" I was told that "these things happen." That should have alerted the doctor that Jeff might also be susceptible to contracting a disease from a live vaccine. When I brought Jeff in for his vaccinations, I asked if he could contract any of the diseases for which he was being vaccinated, and they said, "Probably not, but these things happen." Of course, Jeff did get polio.

Shirley | Knowing what you do now, what things would you have done differently?

Joanne | I would not have had the kids vaccinated with live vaccines. However, the experience was the impetus for me to testify at the Senate hearing to have live vaccines discontinued. When my children were young, healthcare officials knew that six to seven children with immunodeficiencies contracted polio from the vaccine each year, and at the time, that was considered acceptable. But, as a result of the Senate hearing, the live polio vaccine is no longer being used.

Shirley | What type of IG do the boys receive and where? What influenced you to make those decisions?

Joanne | Initially, Curtis and Jeff received one shot of intramuscular IG every 10 days. When they were 6 and 4, respectively, they began IVIG every three weeks, and they were included in a treatment trial. They have now participated in several treatment trials, and luckily, they tolerate all types of IG well. Now, Curtis infuses himself subcutaneously with IG, and my husband infuses the younger children subcutaneously with IG at home every two weeks. The convenience, cost savings and general health of the boys are all better with SCIG. Many factors influenced our decisions about treatment; however, the best, most independent treatment possible for our boys was always primary in our minds.

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

Joanne | We've had our adventures, but so far so good. We have participated in many trials that are free. Our main concerns have been lifetime health insurance caps and making sure the boys receive their infusions in the healthiest environment possible. We have been fortunate as our work has involved changing healthcare companies several times and, each time, the calculation for the cap is restarted. I made it my business to learn as much as possible about insurance and to fight for our rights. While I know that a group plan cannot deny us insurance, several times, we have had to request a case manager from our health insurance company. It was only after convincing our current health insurance companies that they would save a great deal of money by letting my husband administer the boys' infusions at home that we were able to make that change.

Shirley | Has receiving IG helped the boys?

Joanne | The IG has helped immensely, and I can always tell when they are due for an infusion. They also take antibiotics prophylactically so they are rarely sick now.

Shirley | Have you received any support?

Joanne | My husband and I are a team, and he is very supportive and capable. Knowing that I could never give the boys needles, I was thankful that he felt capable of learning how to do it. I do my part by taking care of the supplies and the record keeping. We are both training our two younger boys to take over their own care when they are older.

My husband's family is very supportive. And, of course, the Internet and the specific associations, such as the Immune Deficiency Foundation and Jeffrey Modell Foundation, are very helpful. Initially, I had to rely on what the doctors told me; now, a whole new world has opened up. *IG Living* magazine has also been a great source.

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

Joanne | The best advice is to be your child's advocate. No one knows your child like you do, and you can make a difference! The worst advice was not to have my third son. I was told this when I was already pregnant, and I wouldn't trade him for anything. We hoped he would not be affected, but he is, and we deal with it.

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

Joanne | Keep records, set an example, explain everything and learn as much

as you can about your children's healthcare needs, so that you can teach them to be independent.

Editor's Note: While the polio vaccine is no longer live, in part because of the Senate hearing at which Joanne testified, it is important for readers to know that there still are live vaccines that can pose risks to children with autoimmune disorders who are not yet diagnosed. Such vaccines include mumps, measles, rubella, chickenpox and rotavirus. To date, only the state of Wisconsin screens newborns for immunodeficiencies to alert doctors to this risk. See the news story about rotavirus on page 9 of this issue.

Resources

X-linked agammaglobulinemia (XLA) is also known as Bruton Agammaglobulinemia, an inherited immunodeficiency disease caused by mutations in the gene coding for Bruton tyrosine kinase, a substance critical to the maturation of pre-B cells. Information can be found at <http://emedicine.medscape.com/article/1050956-overview>.



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 stepmother of five.

Ask Kris

By Kris McFalls

Have a question? Kris McFalls, IG Living's patient advocate, 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.

Jill: What have you heard about the deleterious effects of eating soy foods on those with autoimmune disorders?

Kris: In my kitchen hangs a sign, "I have a kitchen because it came with the house." For that reason, I asked Jill Weisenberger, a registered dietician and nutrition expert, to address your question.

Jill Weisenberger: There is so much conflicting information on the Internet that it's hard to know just what to believe. Even when reviewing the scientific literature, it's hard to come to strong conclusions. Research suggests that infants who are fed soy-based formula are more likely to develop autoimmune thyroid disease than babies who are fed breast milk. We also know that soy foods may interfere with the absorption of synthetic thyroid hormone. So, if you take this hormone, wait a few hours before eating soy products, but you needn't avoid them altogether. In addition, animal research — that may or may not apply to humans — suggests both positive and negative effects of soy compounds on lupus.

Keep in mind that soy is an excellent source of protein and other nutrients. Often, it displaces some not-so-healthy foods like greasy burgers and meat- and cheese-loaded pizzas. But remember that soy supplements and processed soy foods like soy chips and bars are not the same as whole soy foods

such as tofu and edamame beans. If you have concerns about soy, it's probably wise to avoid processed soy foods and enjoy whole soy foods in moderation just like you would enjoy other whole foods.

With all medical questions, you should ask your pharmacist and doctor for specific answers.

Frank: What is the normal immune globulin dosage for a male weighing 200 pounds with chronic inflammatory demyelinating polyneuropathy (CIDP)? And, how often should it be given?

Kris: Although all current intravenous immune globulin (IVIG) products have been used to treat CIDP, at this point, only Gamunex has FDA approval for CIDP. To answer your question, I referred to the Gamunex package insert to find the recommended dosing is an initial loading dose of 2 grams per kilogram of body weight over two to four consecutive days. After the initial treatment, a maintenance dose of either 1 gram per kilogram in one day or .5 gram per kilogram over two consecutive days every three weeks is recommended.

To calculate your weight in kilograms, divide the number of pounds, in your case 200, by 2.2 — equaling roughly 90.9 kilograms. Therefore, your loading dose according to the package insert would be about 181.8 grams, and your maintenance dose would be about 91 grams. Your doctor may also adjust your dose depending on the vial size of your IG medication available at your clinic or specialty pharmacy. For instance, if your medication comes in a 10% solution and vial sizes come in 10 grams and 20 grams, your doctor may elect to give you 90 grams of medication as your maintenance dose.

Of course, with all medical questions, you should ask your pharmacist and doctor for specific answers. Depending on your disease and clinical manifestations, your doctor may choose to take a different approach. Taking a proactive role in your care by keeping a health diary, documenting your response to treatment and any improvements and declines you notice will help your physician know how to best tailor your care.

You can find the Gamunex package insert at www.talecris-pi.info/inserts/Gamunex.pdf. ■



KRIS MCFALLS has two adult sons with chronic diseases treated with IG. She is formerly a physical therapist assistant, and currently, she is IG Living's full-time patient advocate.

Choices

By Ever Fecske

SOME DAYS, IT feels like I picked the short straw, when in actuality, I didn't pick anything at all; I just got it. Everyone like me who suffers from a chronic illness knows that we didn't choose our diagnosis. But we can choose how to deal with it. We can choose to think of our illness as either a curse or a gift. It's like the old cliché: The glass can be either half empty or half full.

We have the opportunity to choose the most positive options that we have for the life that has been given to us. This choice is not any different from the choice a person has to make when deciding to leave a job or start a new one. It is our choice to deal with our illness as a different path or a new opportunity. We have the power to look at life in ways that make us the happiest we can be. We can choose to have compassion for ourselves. We can choose to love who we were, are and will be.

So, if being positive is a choice, why can this sometimes be the most difficult choice we have to make? For instance, there are days when I have a wicked sinus headache and all I want to do is sleep. Invariably, it seems there is always music playing in one room, a television on in another, the lawn is being mowed and my brother is practicing the electric guitar. How can I deal with all the chaos when I am feeling so chaotic? I can scream and yell and get irate; that's certainly the impulse I feel, and it's an easy release. Or, I can find a positive outlet. I can take some Sudafed and go



for a walk, or take a bath. No one would argue that this would be a better choice, but at the time, it is a tough one to make.

What choices do we have when our doctors are not telling us what we want to hear? Either they urge us not to try subcutaneous infusions, or they want us to continue on a medication we really can't stand, such as prednisone. In these instances, we can make the choice to get angry and frustrated, or we can take a deep, cleansing breath, let it out and think about what would make us happy. One road to satisfaction and diverting our frustration is to become more proactive; we can go to the library, Google, Twitter and reach into the world and do our own research. We can even try to find a doc who will work with us and give guidance and hope.

My point is: We all need to work on making new choices — ways to examine our options for happiness and to avoid those dark, negative places that are filled with frustration,

hopelessness and just useless dead ends. My new perspective is that choices can dictate our destiny. If we choose to have negative thoughts and lead ourselves into negative places, we will no doubt live a negative existence. But if we can make it a choice to think positively, find the good in every circumstance and act positively daily, we will absolutely be happier and more productive. How hard is that choice?

Get started right now: Think about your life, and write down all the positive things you can do to make it better. Be productive, be giving and understanding, and start making a habit of it. It's your choice. ■



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

She is a fashion design student, loves spending time with her boyfriend, family and bulldog, Dunkin, and can't get enough of writing, cake decorating and anything that sparkles!

An Audience of One



By Cheryl L. Haggard

WHEN I SPEAK publicly about raising three children with a primary immune deficiency, I often receive comments like: “My life isn’t nearly as bad as I thought it was now that I know what your family really goes through!”

Or: “Now when I’m on my pity pot, I’ll remind myself I could be you.”

And my favorite: “Forget antidepressants. You’re better than poppin’ Prozac!”

Backhanded compliments like these do spur me on; caretaking the chroni-

cally ill is not for sissies. However, I do get weary repeating stories like how I backed into a parked hearse at the hospital where Caleb was recovering from sinus surgery. It took my insurance agent 30 uncontrollable minutes of laughter to ask me, “Was anybody hurt?”

Please, don't get me wrong. It is wonderful to know that what we go through as a family is not in vain, and that some think of us as modern-day heroes. From time to time, however, I need someone to gently unscramble the Dr. Seuss-like mushy-mush feelings I have raising Calvin, Caleb and Molly.

So, like clockwork, I make an appointment to see Becca, my non-emotionally attached, once-a-week mental fix.

Becca has gently guided me through the maze of suing our insurance company, and has helped me when the kids' illness has me freaked out like a cat in a room full of rockin' chairs. Becca has befriended Molly, joining her on a justice journey to tackle questions like, "Am I the only 7-year-old who takes sub-Q?" For son Caleb, Becca has shown him how to recycle a syringe and turn it into a high-caliber water pistol. And, Becca has been my tour guide on a bumpy, long and sometimes nauseatingly windy road called "Grief." Grief — as in losing my body — because a few months ago, I was diagnosed with ankylosing spondylitis (a degenerative autoimmune disease of the spine), and just a few days from writing this, my dad lost his battle with common variable immune deficiency.

Basically, Becca has seen me through the toughest year of my life, despite my public platform: Laughter makes good medicine. And at a recent session, I got a dose of my own prescription.

Becca and I had been tossing around the topic of people being habitually late to things, specifically my problem with it. I've always explained, "I'm never late, everybody else is early."

Becca smiled and said my argument was, "Very cute. Narcissistic, but cute."

Of course I had no idea what she was talking about — this being late — because I was into self-absorbed babble. I was obviously clueless because I was running fashionably "late" for Becca's appointment for the umpteen-millionth time.

I pulled into "my" parking spot, opened the visor mirror, wiped a bit of clear gloss on my lips and then flicked a poppy seed out from a front tooth (a leftover from my morning's muffin).

A gentle Idaho rain woke my senses as it drip-dropped on the sidewalk in front of me. It was a beautiful day, and I was looking forward to sharing with Becca how well Molly had been coping with my doing her subcutaneous infusions.

The crisp air matched my fresh mindset. "It's going to be a great session!" I thought. I grabbed the front office door handle, but the door didn't open! I shook the handle and tried again to no avail. I cupped one hand over another and said the magic words, "Open you stinkin' stupid door!" That didn't help, either.

I looked at my purse-sized calendar just to make sure I was there on the right day.

Then a horrific thought crossed my mind: Did I play my last obnoxious card and has my own therapist, my Becca, fired me?

The last idea I came up with, other than breaking and entering, was to call her cell that she rarely answers. Just leave a message that you tried to meet with her; she'll understand.

I choked back tears as I dialed Becca's

phone. The familiar brrrrriiiiiinnng interrupted my thoughts until, "Hello?"

"Becca? Is that you?" I trembled in shock that she answered her phone.

"Yes. Who's this?"

"It's me, Cheryl. Where are you?"

"I'm in my office. Where are you?" she asked with caution.

"Outside, at the front door of the office," I answered anxiously, bracing for impact.

As she rounded the corner, she exchanged her phone for a set of keys to unlock the door. She greeted me with her familiar, friendly smile, and her comforting countenance brought relief to my self-tortured soul.

We laughed and celebrated my overactive brain cells conjuring up a story as silly as my therapist firing me, although it has happened before.

"Are you kidding? I'd never fire you! You are the kind of client that keeps a therapist sane!" Becca announced, interrupting our "Kumbaya" moment.

Whodathunkit! Becca and the audiences before her that know our family's silly shenanigans were already reaping the benefits of laughter! It was finally time for me to take a little bit of my own medicine.

So, if you see me with a goofy grin on my face, don't worry! I'm just yukking it up with an audience of one. 🍷



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.

O Captain, My Captain



By Mark T. Haggard

“LET’S GO, GUYS!” I yelled up the stairs as two of my three kids descended from their rooms. “Where is Caleb?” I asked, uneasy about getting everyone ready for the trip we had on our schedule.

“Caleb Airlines,” I heard from overhead. “Flight 427, you have final clearance to land on runway 4-0-9er.”

“Ladies and gentlemen, please return your seat backs and tray tables to their upright position.”

Then, he emerged. He wore dark blue dress pants above black “spit-shine” shoes, a dark blue jacket that didn’t match the pants and a gray button-down shirt with red stripes that didn’t match anything. He topped off the ensemble with his white pilot’s hat. At one time, the hat was an heirloom, traded to my parents by a pilot of the Soviet Air Force during their trip to Russia in 1992. It was beautiful, brilliant white all around,

flat and round on top, angling down to the back, a black bill at the front with the bright red hammer-and-sickle front and center.

I had kept the hat stored in my garage, waiting for the time when I could sell it on eBay for four figures. That was until I saw my then-4-year-old son wearing it while riding his bicycle, a Boeing 737, he said, flying between Boise and Seattle. When it fell from his head a few times, I saw



my four figures headed down the gutter. Now the hat is Caleb's, and he makes better use of it than I ever did.

As our flight to California was leaving in two hours, I didn't have time to make my son change his clothes, drive to the airport, get through airport security and get to our gate, so we left, my son with his hat and flight plan in hand, and a smile on his face.

Adding to the frustration of having

my kids with me was that my wife was already in Los Angeles expecting me to arrive with them, well-fed and well-groomed. I had four hours and a stop in Salt Lake City to prepare for the scolding I would receive upon our arrival at LAX.

During the first leg of our flight, I was sitting in 19E looking past my son's hat and out of the postage-stamp-sized window at the browns and yellows of the passing intermountain landscape. I finagled the last cube of ice out of the bottom of my plastic cup and crunched it into oblivion, realizing that my next drink was 30 minutes away.

Just then, a smiling flight attendant stopped in the aisle next to our row and stared at my son sitting next to me. "Does the captain want more Coke?" she asked kindly.

I furrowed my eyebrows as the hat in 19F bobbed up and down.

"More Coke?" I asked my son, watching the flight attendant pour another plastic cup of the dark drink. "How do you rate?"

"He's the captain," the flight attendant replied. "You're just another passenger," she added, looking at me and piling on insult to my injury.

Caleb took his additional drink, smiled at me, and gulped down more refreshment.

Getting off of the plane in Salt Lake, we were greeted by a ramp worker staring at the hat on my son's head. "You wear hat from my home country," he said in heavily accented, broken English.

"Really?" I replied, hearing the Slavic in his voice.

"Da!" he announced. He looked at my son and said, "You are Captain of Russian Air Force," and snapped an open-palmed, Eastern European-style salute. Caleb smiled broadly. The Russian shook my son's hand and smiled back just as wide.

Later, it struck me that we parents spend a lot of time trying to form our children in our own image, particularly when we go out in public. I had no intention of letting Caleb get on an airplane and go to L.A. looking like he did. And, yet, had he dressed the way I wanted, he would have been just another passenger, like the thousands before who had flown in 19F, staring out the window and sucking down one thimble-sized cup of Coca-Cola product. Caleb wanted to stand out, to be put on the stage, to have people notice him. And notice him they did.

Oftentimes, our PIDD kids get recognized for the wrong reason: he's chronically ill; he's got too many absences at school; he can't play right now. But for one day last month, Caleb was recognized for something positive, something that he wanted. He was the Captain.

That hat, now soiled after much overuse, is more valuable than I ever would have imagined. ■



MARK HAGGARD is a high school teacher and football coach, and has three children, two of whom have CVID. He and his wife, Cheryl, also operate *Under the Hood Ministries* at www.underthehoodministries.org.

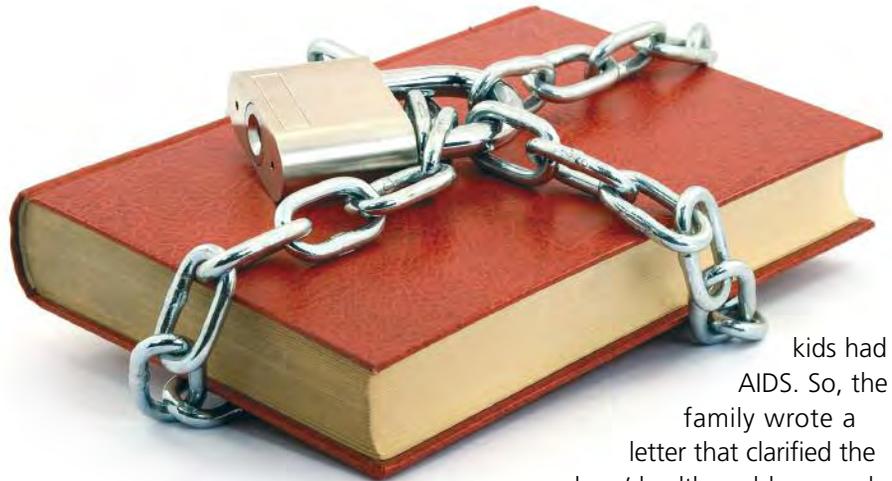
To Disclose or Not Disclose

The personal decision to tell others about a condition lies in what the individual feels most comfortable with and how it's communicated.

By Jennifer Kester

IN YEARS PAST when the McFalls family would attend church on Sundays, someone new to the congregation would hear the whirring pumps and invariably ask, "What's that noise?" Then a church regular would lean in and whisper, "That's just the McFalls boys. I'll explain later." Brothers Keegan and Konner infused at church and were pretty open about their common variable immune disease (CVID) when they were younger, but the two take opposite approaches today. Keegan, 22, remains candid about his condition, not hesitating to tell friends, classmates or anyone else. But Konner, 24, prefers to keep quiet about his condition. This difference is not uncommon. Many wrestle with the decision of when — or whether — to reveal their medical condition to others.

"I don't want people to feel sorry for me," Konner says. "I want them to get to know me and who I am, not the things I have. I'm the kind of guy who doesn't like a lot of sympathy." Konner was so adept at hiding his CVID that when he lived in a dorm, his roommates had no idea. "I would just sit in my room doing my treatment with my door closed, work on homework or watch a movie," the Lacey, Wash., resident says. When he did reveal his condition to some of his friends, they were surprised, since Konner is always on the go and seems relatively healthy.



On the other hand, Keegan feels it's important to tell others about his CVID. "All my friends pretty much know already," the Brigham Young University student says. He adds that he tries to make a joke out of it and that he's never had a negative reaction. "I'd be like, 'Are you afraid of needles?'" he says, making the experience less awkward for his friends. "It's something that's just part of my life. I don't have a problem with it, and if they have a problem with it, it's their problem."

The fear of what others think or how they'll react is a big reason many people with chronic conditions don't discuss their diagnosis with others. But some argue that's precisely why people should talk about it: It normalizes it and provides a chance to educate others. Kris McFalls, Keegan and Konner's mother, says that back in the early '90s, when her sons were young, people thought the

kids had AIDS. So, the family wrote a letter that clarified the boys' health problems and left it on file at the school. "You take the fear out of it, and that's what it was — fear," she says. "They didn't understand back then. I felt educating them and teaching them to be more open about it took the fire out of it."

While Kris says it's a very personal decision, safety concerns can be an overriding factor. "For my kids, my biggest worry wasn't that someone would walk away from them thinking they would get contaminated, but I worried about them being unwittingly exposed to something," she says. Kris says it concerned her that Konner didn't tell any of his college roommates. "Yes, it's his business and that's his right, but if he had a problem no one would ever know. They didn't know that they should stay away from him if they had a cold."

Like the McFalls brothers, Jordan Leventhal grew up in a split-decision household: His father and sister keep

their CVID under wraps, but the 21-year-old has no qualms about revealing his condition. "I have CVID, CVID doesn't have me," he says. "I think it's important because people need to learn about it, and there needs to be more public awareness of what it is. It's something we have to be proactive about, something we're getting money for to do testing and research."

Leventhal finds that telling others gives him a good support base. When he was in boarding school, his friends would keep him company during his infusions. Now as a student at Cuyahoga Community College in Cleveland, Ohio, he works with the college disabilities office so that his teachers understand his condition. The paramedic major isn't worried about disclosing his condition to potential employers after graduation. "They don't need to know about it until I take a job," he says. "Legally, they can't ask about it and I don't legally have to disclose it. And if I do disclose it, I have the Americans with Disabilities Act [to protect my rights]."

Telling employers about a chronic illness is a common fear. Arizona mom Kelliann Conner says her and her two daughters' primary immune disease has made it hard in the workplace. "I have lost jobs because of ... missing too much time," says Kelliann, 40, a now-unemployed medical worker who had to stay home often to take care of her sick kids. The condition also became an issue at work because of the cost of health insurance. Kelliann's husband was a vice president and the acting president of a small company when he was approached by an insurance agent who said that

the family of one of the employees was costing a fortune. The agent, who had no idea this was the Conner family, insinuated that if the employee wasn't going to be there the following year, the agent could renew the company's policy at the same rate. Otherwise, the premium would be much higher.

People with chronic conditions aren't afraid of telling only employers about their illness. Telling loved ones proves to be an obstacle as well. Many find it hard to gauge when to tell someone they're dating.

Erika Lawrence, an associate professor in the department of psychology

The fear of what others think or how they'll react is a big reason many people with chronic conditions don't discuss their diagnosis with others.

at the University of Iowa and an *IG Living* advisory board member, says that while the decision about whether to inform others depends on the context — how well you know the person and what kind of person he or she is — revealing your condition adds intimacy and increased support, which in turn offer health benefits: "Some of the research I do shows that appropriate support really buffers the effect of stress on physical and psychological health. So if one is feeling the stress of being ill and

not allowing people close to them to show support, that can actually increase the symptoms."

The first things people must do when considering whether to disclose their condition is to carefully choose whom to tell and to find the right time, Lawrence says. Then, figure out what the concern is. Instead of judging others' fears, just accept them and don't let them prevent you from telling others. Most important, she says, people have to be comfortable with their conditions and want the support. People have to let their loved ones know how they want them to respond and what they need from them. "In a work relationship, it's a lot more complicated," Lawrence says. "But in general, these kinds of disclosures — if the person can be clear about how he wants to be treated — it can actually increase the quality of the relationship."

For those still weighing whether to disclose a chronic condition, Leventhal offers some advice: "Take the risk and tell them. You don't want to tell people the first day you meet them, but on the other hand, there's nothing to be ashamed of. You didn't do it to yourself. It happened to you." ■



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

Editor's Note: For a discussion about the legal obligations of disclosure, refer to the story on page 10.

An Overview of Pumps

By Nancy Creadon, RN

Infusion pumps allow for the mechanical administration of infusions when it is impractical for a person to manually infuse medication. Many factors are considered when ordering an infusion pump, including expense, reliability, volume of medication to be infused, type of medication to be infused and length of infusion, to name a few. In addition, infusion pumps can be programmed to provide continuous infusions, intermittent infusions or bolus infusions.

Continuous infusions usually consist of pulses of infusion with a rate dependent on the programmer's specifications. The pump can be titrated up or down simply by changing the flow rate of the infusion. Generally lasting for several hours and possibly for days, many types of intravenous therapies can be given with this method. Syringe drivers, another type of pump offering a continuous infusion, also provides pulses of medication at a set rate. However, they also produce high, but controlled pressures and, therefore, are good choices for subcutaneous infusions. Syringe drivers are also useful for delivering IV medications over the course of several minutes, which saves staff time and reduces medication errors.

Intermittent infusion pumps are well-suited for the patient receiving antibiotic therapies. They can be programmed to infuse at selected times throughout the day or night.

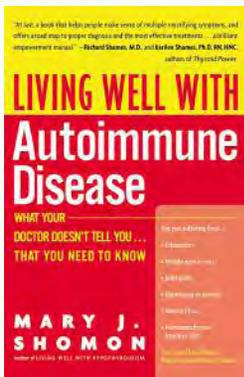
Bolus infusion pumps, or patient-controlled infusion pumps, allow patients to receive medication based on their symptoms or comfort level, at preset intervals. This type of pump is generally utilized for patient-controlled analgesia.

It is important to note that many pumps come with their own proprietary tubings, syringes and cassettes, most of which are not interchangeable. However, some pumps do not use proprietary products, but specific brands and/or sizes must be used. Additionally, many infusion pumps require routine preventative maintenance. It is of critical importance that a pump be checked yearly, or when recommended, to ensure proper infusion rates, volumes administered and timing. ■

NANCY CREADON, RN, is vice president of VaxAmerica, a program offered by the specialty pharmacy of FFF Enterprises, which specializes in biopharmaceutical management and distribution.

Pump Comparison Chart

Pump	Size (pump only)	Weight (battery included)	Proprietary equipment	Rate variable	Cost	Alarms	Fluid capacity per syringe or cassette	Power source	Links
Graseby MS15A	6.5" L x 2.1" W x 0.9" D	6 oz	no	yes	middle	yes	25ml	9V battery	www.marcalmedical.com/GrasebyMS16A_SCIG_IVIGHourlyPump.htm
Intrapump Crono S-PID 50	3.3" L x 2.1" W x 1.6" H	4.93 oz	syringes	yes	high	yes	50ml	CR 123A 3V Lithium battery	www.intrapump.com/ambulatory/cronoS-PID50.htm
Micrel MP101	6.5" L x 1.57" W x 0.9" D	5.6 oz	no	yes	middle	yes	20ml	6 AAA batteries	www.micrelmed.com/interior/products/micropump003.htm
RMS Medical Freedom 60	12" L x 4.5" W x 1.6" H	14 oz	fixed flow rate tubing	no	lowest	no	60ml	manual	www.rmsmedicalproducts.com/Freedom60info.htm
Smith CADD Prizm	5.6" L x 4.1" W x 1.7" D	13.8 oz	cassette with tubing	yes	high	yes	100ml in cassette; more in an IV bag	9V battery	www.mtrhealth.com/product.aspx?pid=322

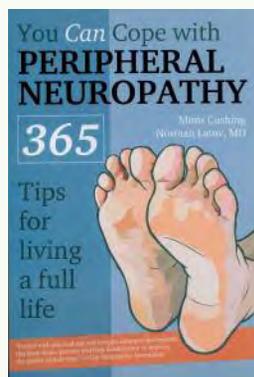


Living Well with Autoimmune Disease

What Your Doctor Doesn't Tell You ... That You Need to Know

Author: Mary Shomon
 Publisher: HarperCollins,
 New York, NY, (212) 207-7000,
www.harpercollins.com

Living Well With Autoimmune Disease is a complete guide to understanding the mysterious and often difficult-to-pinpoint autoimmune disorders. It is written by a bestselling health writer and patient advocate who believes in empowering patients with both conventional and alternative information, resources and self-care tactics that help get a proper diagnosis and life-changing treatment. Featured are first-person accounts from autoimmune disease patients, recommendations and treatment suggestions from some of the nation's leading practitioners, a detailed Risk Factors and Symptoms Checklist that you can take to your practitioner to aid in diagnosis, information on the latest innovative conventional and alternative treatments for autoimmune conditions, a detailed resources section featuring patient support groups, hotlines, websites, practitioners and more to help you in your effort to live well, and a look at the future of autoimmune disease diagnosis and treatment.



You Can Cope with Peripheral Neuropathy

365 Tips for Living a Full Life

Authors: Mims Cushing and Norman Latov, MD
 Publisher: Demos Health,
 New York, NY, (800) 532-8663,
www.demospub.com

You Can Cope with Peripheral Neuropathy, written by both a patient-expert and a doctor, is a resource and guide for anyone living with peripheral neuropathy or for those who suspect they have it but have yet to be diagnosed.

Peripheral neuropathy is a common disease, affecting upward of 20 million Americans, and yet most people have never heard of it. It causes pain and numbness in one's hands and feet. The pain is described by those who have it as a tingling or burning sensation in the limbs, while the numbness is often compared to the feeling of wearing a thin stocking or glove. Because its extent and importance have not yet been adequately recognized, the disease is often misdiagnosed or thought to be a side effect of another disease, such as diabetes, cancer or kidney failure.

The book covers topics that range from what to ask your doctor, to advice on traveling and making your home easier to navigate, to finding a support group, to using vitamins and herbs for treatment. The authors' goals in writing the book are threefold. First, they hope that the medical information will explain how physicians approach the diagnosis and treatment of neuropathy, and answer some frequently asked questions. Second, they want to help people with the 365 tips gathered from exercise trainers, professionals specializing in many different fields, lecturers, neurologists, caretakers, books and other resources. And, last, with the personal histories written by people affected by peripheral neuropathy, they look to inspire and further educate people about this confusing disease.

The Autoimmune Diseases, 4th Edition

Authors: Noel Richard Rose and Ian R. Mackay
 Publisher: Academic Press,
 St. Louis, Mo., (800) 545-2522,
www.elsevierdirect.com

While this edition of *The Autoimmune Diseases* has been in print since 1996, it is now available for a free download at 4ebooks.org. Added to the fourth edition is a more in-depth look at the immune mechanisms underlying autoimmunity and autoimmune disease. The newly incorporated material combines common themes underlying inductive and effector mechanisms and therapies that relate generally to the autoimmune disorders. Also included are tissue-specific interventions to arrest or "cure" autoimmune disease; bone marrow eradication and replacement; basic science and clinical medicine; and boxed points to emphasize key features of each chapter.

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

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Websites

- GBS/CIDP Foundation International: www.gbs-cidp.org

Online Peer Support

- Barbara's CIDP/GBS Site: www.geocities.com/HotSprings/Falls/3420

Evans Syndrome

Online Peer Support

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

Guillain-Barré Syndrome (GBS)

Websites

- GBS/CIDP Foundation International: www.gbs-cidp.org

Online Peer Support

- GBS & CIDP Discussion Forum – UK Bulletin Board (For Ireland and England): www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi
- GBS/CIDP Foundation International Discussion Forums: www.gbs-cidp.org/forums.
- GBS Support Group and Chat Room – UK: www.jsmarcussen.com/gbs/uk/chat.htm

Idiopathic Thrombocytopenic Purpura (ITP)

Websites

- ITP Support Association – UK: www.itpsupport.org.uk
- National Heart, Lung and Blood Institute: www.nhlbi.nih.gov/health/dci/Diseases/Itip/ITP_Whats.html
- Platelet Disorder Support Association: www.pdsa.org

Kawasaki Disease

Websites

- American Heart Association (how the disease affects the heart): www.americanheart.org/presenter.jhtml?identifier=4634
- Kawasaki Disease Foundation: www.kdfoundation.org
- KidsHealth: <http://kidshealth.org/parent/medical/heart/kawasaki.html>

Mitochondrial Disease

Websites

- United Mitochondrial Disease Foundation: www.umdf.org

Multifocal Motor Neuropathy (MMN)

Websites

- The Neuromuscular Center at Washington University: www.neuro.wustl.edu/neuromuscular
- The Neuropathy Association: www.neuropathy.org

Multiple Sclerosis (MS)

Websites

- All About Multiple Sclerosis: www.mult-sclerosis.org/index.html
- Multiple Sclerosis Association of America: www.msaa.com
- Multiple Sclerosis Foundation: www.msfacts.org
- National Multiple Sclerosis Society: www.nationalmssociety.org

Online Peer Support

- Friends with MS: www.FriendsWithMS.com
- MSWorld's Chat and Message Board: www.msworld.org

Myasthenia Gravis (MG)

Websites and Chat Rooms

- Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org

Online Peer Support

- Autoimmune Information Network Inc.: www.aininc.org

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>
--	---

- International Myositis Assessment and Clinical Studies Group: <https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main>
- The Cure JM Foundation: curejm.com

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

Pemphigus and Pemphigoid

Websites

- The International Pemphigus and Pemphigoid Foundation: www.pemphigus.org

Peripheral Neuropathy (PN)

Websites

- Neuropathy Action Foundation: www.neuropathyaction.org

Online Peer Support

- Calgary Neuropathy Support Group: www.calgarypnrs.org

Primary Immune Deficiency Disease (PID)

Websites

- American Academy of Allergy, Asthma & Immunology: www.aaaai.org
- International Patient Organization for Primary Immunodeficiencies (IPOPI): www.ipopi.org
- Michigan Immunodeficiency Foundation: www.midf.org
- National Institute of Child Health and Human Development (NICHD) (Click on "Health Information and Media" tab and search for "primary immunodeficiency": www.nichd.nih.gov)
- New England Primary Immunodeficiency Network: www.nepin.org
- Rainbow Allergy-Immunology: www.rainbowbabies.org/immunology
- Team Hope (for families and patients in New England): www.teamhope.info

Online Peer Support

- Jeffrey Modell Foundation Message Board: www.info4pi.org
- Rhode Island peer group: <http://health.groups.yahoo.com/group/RhodeIslandPID/>

Scleroderma

Websites

Scleroderma Center: <http://scleroderma.jhmi.edu>

- Scleroderma Foundation: www.scleroderma.org
- Scleroderma Research Foundation: www.srfcure.org

Online Peer Support

- CureZone.com: 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
- Autoimmune Information Network Inc.: www.aininc.org
- Living with Stiff Person Syndrome (personal account): www.livingwithsps.com

General Resources

Other Organization Websites

These organizations provide information about various disease states, which can be found by conducting a search of the disease state name.

- Advocacy for Patients with Chronic Illness: www.advocacyforpatients.org
- Alliance for Plasma Therapies (fair access to plasma therapies): www.plasmaalliance.org
- American Autoimmune Related Diseases Association (AARDA): www.aarda.org
- American Chronic Pain Association (ACPA): www.theacpa.org
- Band-Aides and Blackboards: www.lehman.cuny.edu/faculty/jfleitas/bandaides
- Cleveland Clinic: www.clevelandclinic.org/health
- eMedicine from WebMD: emedicine.medscape.com
- FamilyDoctor.org: www.familydoctor.org
- Johns Hopkins Medicine: www.hopkinsmedicine.org
- KeepKidsHealthy.com (pediatrician's guide to children health and safety): www.keepkidshealthy.com
- Kids Health (medical and emotional impact of caring for an ill child): www.kidshealth.org/parent/system/ill/seriously_ill.html
- Mayo Clinic: www.mayoclinic.com
- National Committee for Quality Assurance (detailed report cards on health plans, clinical performance, member satisfaction and access to care): www.ncqa.org
- National Institute of Neurological Disorders and Stroke (NINDS): www.ninds.nih.gov/disorders/disorder_index.htm
- National Institutes of Health: www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm
- National Organization for Rare Disorders (disease-specific support groups and virtual communities for patients and caregivers): www.rarediseases.org
- Office of Rare Diseases Research: rarediseases.info.nih.gov
- Patient Advocate Foundation (patient access to care, maintenance of employment and financial stability): www.patientadvocate.org



The nonprofit Patient Services Incorporated, www.uneedpsi.org, specializes in health insurance premium, pharmacy co-payment and co-payment waiver assistance for people with chronic illnesses. (800) 366-7741

- WebMD (medical reference): www.webmd.com

Education and Disability Resources

- Americans with Disabilities Act of 1990: www.ada.gov
Provides protection for people with disabilities from certain types of discrimination, and requires employers to provide some accommodations of the disability.
- Continuation of Health Coverage — Consolidated Omnibus Budget Reconciliation Act (COBRA): www.dol.gov/dol/topic/health-plans/cobra.htm
- DisabilityInfo.gov: www.disabilityinfo.gov
U.S. Federal government's disability-related information and resources.
- Individuals with Disabilities Education Improvement Act of 2004: <http://idea.ed.gov/explore/home>
- 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.
- Social Security: www.ssa.gov/disability
- U.S. Department of Education Website: www.ed.gov
This federal government website offers a parents section titled "My Child's Special Needs."
- 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.

Medical Research Studies

- ClinicalTrials.com: www.clinicaltrials.com
This site has a registration form to request that you be notified about recruitment for future studies.
- ClinicalTrials.gov: www.clinicaltrials.gov
A registry of federally and privately supported clinical trials conducted in the United States and around the world.

Food Allergies

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

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
- IVIG Privigen: www.privigen.com
- SCIG (subcutaneous immune globulin) Vivaglobin: www.vivaglobin.com

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
- Micrel Medical Devices: www.micrelmed.com
- Norfolk Medical: www.norfolkmedical.com
- Repro Med Systems, Inc: www.rmsmedicalproducts.com
- Smith Medical: www.smiths-medical.com/brands/cadd

Have something to add to these pages? Please send your suggestions for additions to the IG Living Resource Directory to editor@IGLiving.com.



Is Your Nurse an IG Professional?

3rd Annual Advanced Practicum for Professionals Providing Immunoglobulin Therapy: IVIG and SCIG

Saturday, October 24, 2009

Hilton Garden Inn
Cleveland, OH

Course Director:
Kimberly Duff, RN, BSN

For more information:
216-983-1239
or 800-274-8263

medcme@case.edu, <http://cme.case.edu>

CEUs for nurses and pharmacists will be provided

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

PRSR STD
US POSTAGE PAID
ESCONDIDO, CA
PERMIT NO. 390

Forecast: Virus Showers Ahead!

Prepared for a
Stormy Flu Season?
We've Got You Covered!

No pre-payment

On-time delivery

Multiple presentations
from the top manufacturers

Now the only risk is
not being prepared!

Visit MyFluVaccine.com to order and for terms and conditions.



YOU PICK THE QUANTITY • YOU PICK THE DATE • WE DELIVER

 | (800) 843-7477 | www.MyFluVaccine.com

Brought to you by FFF Enterprises, Inc., the nation's largest and most trusted distributor of flu vaccine and critical-care biopharmaceuticals.

©2009 FFF Enterprises, Inc.