

How Exercise Benefits the Immune System

**Insurance Disputes:
Responding to
Claim Denials**

**Understanding
and Treating
IG Side Effects**

Understanding Your
Rights Under HIPAA

Learning to Care
for the Caregiver

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About IG Living

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

IG Living, (ISSN 1949-4548), 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.

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MATTHEW DAVID HANSEN,
DPT, MPT, BSPTS
Physical Therapist

Exercise and the Immune System

"Years of evidence support the claim that the right amount of certain types of physical activity can promote good health and improve symptoms in individuals with conditions of impaired immunity."



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

How to Handle Insurance Disputes

"If a claim denial is due to an alleged lack of medical necessity, patients must prove that the item in question is medically necessary."



KRIS MCFALLS
Patient Advocate, IG Living magazine
Understanding and Treating IG Side Effects

"Both the FDA and European regulatory authorities are encouraging patients and healthcare professionals to report adverse drug reactions."

Treating Asthma

"Patients who regularly monitor their peak flow numbers have a better chance of keeping their asthma under control and often can spot trouble before it becomes a crisis."



TERRY O. HARVILLE, MD, PHD
*Consultant and Medical Director,
Special Immunology Laboratory,
University of Arkansas for Medical Sciences*

Immunology 101: The Beginning

"One of the problems with understanding the immune system involves the terminology, especially with regard to the classifications of its various components."

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.

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IG community through education,
communication and advocacy*

A community service from
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Assistant Editor **Cheryl Brooks**

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Ben Drolet

Proofreader **Jackie Logue**

Contributing Writers

Ever Fecske

Cheryl L. Haggard

Mark T. Haggard

Matthew David Hansen, DPT, MPT, BSPTS

Terry O. Harville, MD, PhD

Jennifer C. Jaff, Esq.

Kris McFalls

Contributions Past and Future



THIS ISSUE, we embark upon our fifth year of publishing *IG Living*. When the magazine first debuted in 2006, there was no other publication dedicated to the many IG patients across the nation who were thirsting for information and answers to long-sought-for questions. Today, there is still no comparable publication, and an entire community has evolved from our readership, which exceeds 25,000. The magazine has become a strong platform for sharing information about living with immune-mediated diseases, and that could never have been possible without the contributions of many in this community.

These contributions have made *IG Living* an educational tool to provide you with the necessary information to promote your, your patients' or your loved ones' health. They also have put personal faces on the stories of those who struggle to become healthy. What's more, they are advancing our cause, as the majority of our contributors serve as advocates for our community's issues.

And, our concerns are indeed complicated ones — from understanding disease states and diagnoses, to comprehending the treatment and reimbursement issues. How fortunate we are to have respected specialists willing to share their knowledge to provide guidance for our readers! Some of these specialists serve on our advisory board, and others contribute as needed, such as Jennifer Jaff who provides legal knowledge, Jill Weisenberg who writes about nutrition issues, Erika Lawrence who provides family and individual counseling advice, and Matthew Hansen who dispenses exercise recommendations.

Now, in this issue, we introduce as a regular contributor Dr. Terry Harville who kicks off his Immunology 101 column on page 7. In collaborating with Dr. Harville for many years about patient questions,

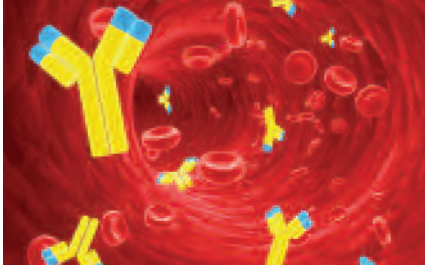
Patient Advocate Kris McFalls relies on Dr. Harville's answers to be detailed, enlightening and on a level patients can understand. Which is precisely why we asked him to author this new column that will examine the components, development, function and interactions of the immune system, a complex and often misunderstood subject.

Moreover, we have other community members willing to share their personal stories, many of which appear in our features and LifeStyle section. For instance, Mark and Cheryl Haggard continue to give us lighthearted glimpses at raising kids with primary immune deficiency disease. Ever Fecske passionately describes a young woman's challenges living with CVID and interstitial lung disease. And, our Let's Talk column spotlights a range of patients in a question-and-answer format. In addition, we have added another LifeStyle column this issue. Transitions, on page 36, is intended to expand our horizons with personalized views of people in our community who have transitioned from one state of living to another by overcoming hurdles they face living with their disease. If they can do it, so can you.

All of these contributions advocate for our community by drawing attention to the many different immune-mediated diseases and the issues individuals face when suffering from one or more of them. As we move into our fifth year of publishing, I would like to extend thanks to all who have helped our community evolve, as well as invite even more of you to be part of it. ■

To your health,

Ronale Tucker Rhodes, MS, Editor



Immunology 101: The Beginning

By Terry O. Harville, MD, PhD

I AM HONORED to be asked to write this column on the immune system. I have been studying, teaching and performing research on the immune system since the 1980s, as well as diagnosing and managing patients with immunologic disorders (immunodeficiencies and autoimmunities). And, it has been interesting to see the changes that have come about. Indeed, many of the items I will discuss in this column were not known when I began my journey with immunology.

Immune System Terminology

One of the problems with understanding the immune system involves the terminology, especially with regard to the classifications of its various components. The problem is that some of today's terminology has been held over from the earliest understandings of the immune system, derived mostly from the study of simple organisms. Over time, a portion of the terminology may have lost some relevance with better understanding of the development and functions of immune system components (especially with the study of more complex organisms and humans). But unfortunately, the continued use of the older terms still causes confusion. For example, sometimes major divisions of the immune system may be listed as innate or adaptive, or as intrinsic or acquired, or as humoral or cellular. These terms are meant to imply clear distinctions, but in reality, their meanings may overlap to varying degrees. Therefore, my objective in this column is to provide a clearer understanding of the immune system. To do this, I will attempt to explain, in some detail, the components, development, function and interactions of the immune system.

Why an Immune System?

Where do we start? As Glinda the Good Witch said, "It's always best to begin at the beginning." An important first question is, "Why do we have immunity?" The general answer is to protect us from all of the things that are trying to infect us. But, this is not totally true. Interestingly, the reason organisms originally developed an immune system was probably to allow for fidelity of reproduction — in other words, to identify "what belonged to self" and

"what was not self," in order to allow the correct cells to divide and grow into new organisms. Indeed, this concept has continued and expanded into our modern immunity. The manner in which the immune system grows and develops within an individual allows it to "know oneself." Therefore, the immune system develops to recognize "self" and discriminate "non-self" so that it can avoid attacking "self" and attack only "non-self."

This is indeed elegant. Instead of truly having to know every pathogen out there, the immune system needs to know only the body that contains it so that "non-self" can be distinguished and attacked. But, the immune system has gone one step further, and it has developed processes to produce components capable of recognizing every pathogen so that it can specifically recognize and attack pathogens.

When all of this works well, we are happy. But if there is failure along the way, we are not so happy. Deficiencies in these processes result in immunodeficiencies, and abnormal activity or overactivity in these processes results in autoimmune disorders. Therefore, some redundancy is present to help if some components are deficient, and careful control is needed to help avoid autoimmunity. Unfortunately, this redundancy may not be sufficient, especially when major immune system components do not function correctly. And, sometimes, the control mechanisms go awry and allow autoimmunity.

Caveat Lector!

In my next column, I will begin to discuss the specific components of the immune system, as well as how they develop and function. While this column will likely not be the only source to which readers will look for information about the immune system, please be aware that interpretations can lead to inaccuracies. Therefore, materials should be carefully read, and when possible, several sources should be consulted. ■

TERRY HARVILLE, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, and a consultant for immunodeficiencies, autoimmunities and transplantation.

Making HIPAA Work for You

By Trudie Mitschang



The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was drafted, in part, to allow people with pre-existing medical conditions to change jobs without the risk of being denied health insurance. Obviously, this is a very important factor for anyone with an immune-mediated disease. Understanding the various protections and limitations of HIPAA is essential so that individuals don't forfeit their rights when seeking employment, insurance or medical care.

HIPAA laws offer much-needed protection (with limitations) to those living with a chronic disease. Prior to HIPAA, some employers' group health plans had limited, or even denied, coverage if a new employee had a chronic health condition prior to enrolling in the plan. Under HIPAA, that kind of discrimination is not allowed. If the plan generally provides coverage but denies benefits because a condition existed before coverage began, then HIPAA applies to that situation. But to fully understand HIPAA benefits, it is necessary to decipher some of the Act's specific language.

Defining "Pre-existing"

The term "pre-existing condition" appears often in the HIPAA guidelines. But what constitutes a pre-existing condition? Under HIPAA, group health plans and issuers can exclude a pre-existing medical condition from coverage for up to 12 months (18 months for late enrollees) after an individual's enrollment date, but only if that individual has had a break in coverage of more than 63 days in the past 18 months. In other words, a new employer's plan must give individuals credit for the length of time that they had prior continuous health coverage — as long as there was no break in coverage for 63 days or more

HIPAA laws offer much-needed protection (with limitations) to those living with a chronic disease.

— thereby reducing or eliminating the 12-month exclusion period. So, for instance, if an individual changes healthcare plans, and there is more than a 63-day break in coverage during that change, then that individual is subject to a pre-existing condition exclusion. If, on the other hand, there was a break in coverage of 63 days or less, then that individual is not subject to a pre-existing condition exclusion.

For those individuals who are subject

to a pre-existing condition exclusion, a plan is allowed to look back only six months for a condition that was present before the start of coverage in a group health plan. Specifically, the law says that a pre-existing condition exclusion can be imposed on a condition only if medical advice, diagnosis, care or treatment was recommended or received during the six months prior to the enrollment date in the plan. For example, individuals may have had diabetes for several years prior to starting their current employment. But if they did not obtain medical advice, diagnosis, care or treatment for the disease in the six months before they enrolled in the plan, then the prior condition cannot be subject to a pre-existing condition exclusion. If they did receive medical advice, diagnosis, care or treatment within the past six months, then the plan may impose a pre-existing condition exclusion for that specific condition.

Understanding HIPAA's Main Benefits

In general, HIPAA laws benefit the patient by:

- requiring that all insurers of groups of two or more employees cannot decline coverage on a new applicant for group insurance solely for health reasons.
- limiting the length of time a pre-existing condition exclusion can apply to a newly hired employee to 12 months (18 months for late entrants).
- giving credit for any prior group or individual coverage during the 12 months prior to the effective date of

the new group coverage (for example, if individuals had coverage for nine of the past 12 months, they would have only a three-month exclusion on pre-existing conditions).

- banning pregnancy and prenatal problems from being considered pre-existing conditions.

Keep in mind that a pre-existing condition exclusion relates only to benefits for an individual's (and their family's) pre-existing conditions. If they enroll, they will receive coverage for the plan's other benefits during that time.

Limitations Within HIPAA

Although HIPAA is designed to make it easier to switch jobs without fear of losing health coverage, the law has limitations that individuals should be aware of. For instance, HIPAA:

- does not require that employers offer health coverage.
- does not guarantee that any conditions an individual now has (or has had in the past) are covered by the new employer's health plan.
- does not prohibit an employer from imposing a pre-existing condition exclusion period if the individual has been treated for a condition during the past six months.

HIPAA FAQs

When did HIPAA go into effect?

HIPAA was signed into law in 1996 under the United States Department of Health and Human Services. Healthcare providers nationwide were required to comply with the rules and regulations of privacy protection by April 2003.

What privacy protection is offered by HIPAA?

HIPAA ensures that individuals' private health information is protected by feder-

al law. Individuals have rights regarding their personal information and it also provides specific rules and regulations on who may have access to it.

What are the privacy rights under HIPAA?

- Individuals can ask to see their records and to get copies of them (although they may be charged a fee for copies).
- Individuals can have any corrections that they feel need to be made included in their charts.
- Individuals will be notified if their health information needs to be shared

Although HIPAA is designed to make it easier to switch jobs without fear of losing health coverage, the law has limitations that individuals should be aware of.

with other healthcare providers or specialists, insurance companies or billing personnel.

- Individuals can file complaints if they feel their privacy rights were violated.

Does a doctor have the right to share patient information?

Yes. A healthcare provider can share patient information with:

- other healthcare professionals involved in their care.
- other healthcare specialists for coordination of patients' healthcare.
- other agencies in an effort to report any information that affects public

health, such as dog bites, gunshot wounds or infectious diseases.

- any family, friends or other people that individuals determine as acceptable to help with their medical care, finances and billing.

Can individuals access their own health records?

Yes, they can access their health information whenever and wherever they want. Individuals also have the right to know with whom their information has been shared.

Who else has access to confidential health information?

Anyone directly involved in an individual's care can have access. This includes doctors, nurses, other medical personnel and billing offices. Any specialists or personnel who perform lab tests and diagnostic tests may access individuals' records while they are in their care.

HIPAA and State Law

HIPAA offers many protections to individuals with chronic illness, and is complemented by state laws that may provide even greater protection. Once familiar with the various HIPAA provisions, individuals may want to contact their state insurance commissioner's office to learn about the laws in their area. A good place to start is the National Association of Insurance Commissioners website at www.naic.org. ■

Sources:

HIPAA.Org: www.hipaa.org

HIPAAcomply: www.hipaacomply.com

About.com:

diabetes.about.com/od/doctorsandspecialists/a/hipaalaws.htm

Wikipedia:

en.wikipedia.org/wiki/Health_Insurance_Portability_and_Accountability_Act

TRUDIE MITSCHANG is a staff writer for IG Living magazine.

Research

Genetic Cause of a Type of PIDD Identified



Researchers at the National Institutes of Health have identified a genetic mutation that causes combined immunodeficiency. Using a technique called comparative genomic hybridization, a process by which large amounts of DNA are fixed to a computer chip and analyzed for changes in genes, scientists examined the genes in the tissue samples from five different groups:

11 individuals with unknown immunodeficiencies, people with the variant form of hyperimmunoglobulinemia E syndrome (HIES), people with classic HIES, those with other immunological diseases, and healthy individuals. They discovered that people with the unique form of HIES had mutations in a gene called DOCK8 that led to deletions in parts of the gene. When compared with healthy

individuals, the people with DOCK8 mutations had fewer CD8 positive T cells, immune cells needed to fight viral infections; fewer antibody-producing B cells; and increased numbers of eosinophils, immune cells associated with allergy.

Although further research is required to determine if DOCK8 mutations occur in other people with similar disease symptoms, DOCK8 immunodeficiency syndrome may be a new primary immune deficiency disease. These findings, according to researchers, mean that individuals with this rare disease will be able to receive a more accurate diagnosis — providing comfort for some of those who had battled an unknown immune disease for years. The study was reported in the Sept. 21, 2009, edition of the *New England Journal of Medicine*. ■

Research

Insecticides Linked to Autoimmune Diseases?

New research suggests a link between women's exposure to household insecticides — including roach and mosquito killers — and the autoimmune disorders rheumatoid arthritis (RA) and lupus. The study, which was presented at the American College of Rheumatology's annual meeting by Christine Parks, an epidemiologist with the National Institute of Environmental Health Scientists, examined data from a previous study of almost 77,000 postmenopausal women aged 50 to 79. The study found that women who reported applying insecticides or

mixing them — about half — had a higher risk of developing RA and lupus than women who reported no insecticide use.

The scientists did not find a direct cause-and-effect relationship between insecticide exposure and the illnesses, and they believe that the women have something else in common that accounts for the higher risk. For now, the findings indicate the need for more research on environmental risk factors, better understanding of what factors might explain these findings and what chemicals might be associated with these risks, Parks said. ■



Emergency Service

MediAlert Membership Sponsorships Available



Individuals at risk due to a medical condition, allergy, medication or special need may qualify for a sponsored MediAlert membership offered by the MediAlert Foundation, a nonprofit membership organization dedicated to helping save lives in emergency situations.

Individuals who are unable to afford the fees for enrollment or jewelry can apply for the sponsorship program by submitting a completed MediAlert enrollment form (available at www.MediAlert.org), a brief statement from the person requesting the sponsorship and proof of hardship. Proof consists of a state or federal government assistance program, such as a public assistance card, Medicaid, Medi-Cal (in California) or a food stamp program; an income tax return; a letter or brief statement from a doctor, nurse, school nurse, social/case worker or homeless shelter on letterhead (a physician's prescription pad is acceptable) attesting to the individual's inability to afford the membership fee; or social security disability

insurance. All information should be mailed to Sponsored Memberships, c/o MediAlert, 2323 Colorado Ave., Turlock, CA 95382.

If the application is approved, individuals will receive benefits of membership, which include a stainless steel emblem (engraved with the primary medical condition) on a bracelet or necklace with a personal identification number and MediAlert's 24-hour Emergency Response Center's telephone number, as well as a membership card. Individuals' key medical facts will be entered into the MediAlert Emergency Information Service database, along with their doctor's name and next of kin as part of their personal health record. Access to the information by MediAlert's response personnel is available 24 hours a day through the Emergency Response Center.

For more information about sponsored memberships, contact Aurora Al-Kass, contributions coordinator, at (800) 432-5378, ext. 2492, or (209) 669-2492. ■

Medical Alert

FDA Recalls Needles and Infusion Sets

The Federal Drug Administration (FDA) has recalled Excel/Exelint Huber needles, infusion sets and "Securetouch+" Safety infusion sets manufactured by Nipro Medical Corp. More than two million units are impacted by this recall in distribution nationwide. Recalled needles were manufactured from January 2007 to August 2009. Inspections conducted in October 2009 of Nipro facilities in Japan found that these needles dislodged silicon slivers from the ports in 60 percent to 72 percent of tests. The reason for this coring is related to design and manufacturing processes, which the FDA is continuing to investigate.

Huber needles are used to access ports implanted under the skin of chronically ill patients for repeated access to veins for the withdrawal of blood and infusion of medication, nutritional solutions, blood products and imaging solutions. Patients are advised to contact their healthcare providers if they have any of these infusion kits. ■

Did You Know?

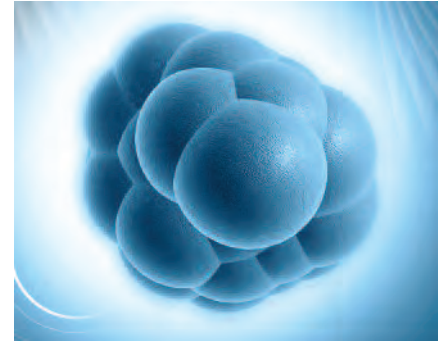
A new radio show for the primary immune deficiency community, called PIDD radio, is intended to raise awareness of the 150-plus types of PIDD, as well as to discuss treatments and concerns. The blogtalk radio station can be accessed at www.blogtalkradio.com/pidd-radio.

Research

New Technique Offers Hope for PID

Researchers may have found a better way for children born with immunodeficiencies to get the help they need from stem-cell transplants, rather than high-dose chemotherapy. In a study reported in the Sept. 12, 2009, edition of *The Lancet*, researchers used immune molecules made by white blood cells (called monoclonal antibodies) to target molecules CD45 and CD53, which are specific to bone

marrow and blood cells. The monoclonal antibodies targeted only immune cells that cause rejection and did not affect other body tissues. The 16 children with primary immune deficiency disease in the study, who were too sick for a traditional stem-cell transplant, were able to avoid much of the toxicity caused by chemotherapy. Patients recovered twice as fast as those given standard treatment, and



almost all are doing well and are expected to have few problems associated with the treatment later in life. ■

People and Places in the News

The **University of Colorado** and **Viral Genetics Inc.** recently signed a license agreement allowing Viral Genetics to develop treatments for autoimmune diseases, graft rejection, HIV and cancer, based on the work of M. Karen Newell, PhD, a professor of biology at the University of Colorado, Colorado Springs. Newell's recent work has uncovered a drug target that may offer a new strategy in treating a wide variety of immune-related disorders and diseases. Her work targets an early interaction in the cascade of events that results in T cell activation, a central component of the body's immune response. This approach allows for more targeted control over the body's immune response against its own and other cells.

Dr. K. George Chandy of the University of California, Irvine, has received a grant related to the

Seattle-based **Kineta's** lead autoimmune drug. Dr. Chandy is a development partner of Kineta, a developer of drugs targeted at autoimmune and viral diseases. The grant from the University of California Discovery Fund covers preclinical studies on its lead autoimmune drug, a Kv1.3 potassium channel blocker. The grant will go to support studies to further characterize the drug ahead of in-human clinical trials.

Lycera Corp., a pharmaceutical company focused on developing novel small-molecule medicines to treat autoimmune diseases, has named **William J. Sibold** as the company's president and chief executive officer. Sibold was formerly senior vice president, U.S. commercial, at Biogen Idec in Cambridge, Mass., where he led the more than \$2.5 billion U.S. business, which consisted of the oncology, rheumatology and neurology therapeutic

areas. Lycera is an emerging leader in the immunology/inflammation field focused on developing new classes of selective small-molecule immune modulators for the treatment of autoimmune diseases, such as rheumatoid arthritis, psoriasis and inflammatory bowel disease. Lycera Corp. is also moving its headquarters to Cambridge.

Dr. Anastasia Daifotis has been appointed senior vice president, clinical development, at **MacroGenics Inc.**, a privately held biotechnology company that develops immunotherapeutics to treat autoimmune disorders, cancer and infectious diseases. Daifotis has had a distinguished 16-year career in clinical development and global medical affairs management at Merck & Co. For the past two years, Daifotis was vice president, global medical affairs, leading the organization that provides medical support and

Technology

JMF Develops Software to Recognize and Track PI

The Spirit Analyzer is new software that can be used by managed care plans to identify undiagnosed patients with primary immunodeficiencies (PI). Developed and owned by the Jeffrey Modell Foundation (JMF), the Software for Primary Immunodeficiency Recognition Intervention and Tracking (SPIRIT) contains a list of more than 350 weighted ICD 9 codes that are matched to the 10 warning signs of PI

to establish low-, moderate- and high-risk categories. Patients who score moderate and high risk are flagged as potentially in need of further testing for PI. The Spirit Analyzer can analyze one million pharmacy and medical claims in approximately 30 minutes. Health plans are able to automatically alert the physicians of those patients with recurring infections that are high and moderate risk

and encourage appropriate assessment, thereby improving patient outcomes and saving healthcare costs. The analyzer is being tested by third-party payers and is being considered by several government agencies, according to the JMF. For more information, go to www.info4pi.org/Documents/Newsletters/JMF-2010-Newsletter_20091105_171850.pdf. ■

information to the franchises, markets, healthcare professionals and patients related to Merck's products and related disease areas.

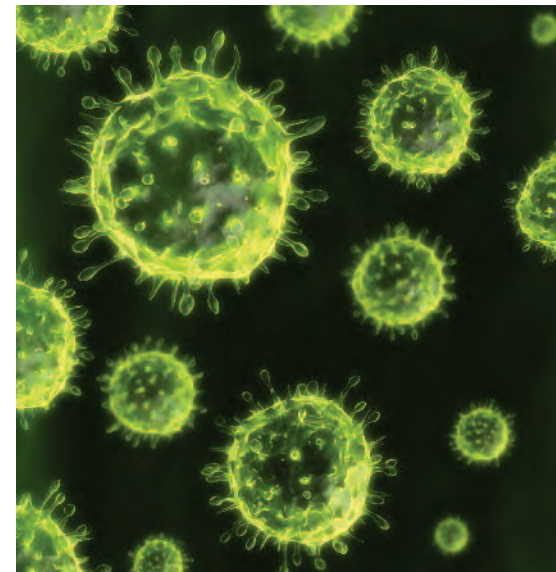
Trillium Therapeutics Inc. (TTI), a biopharmaceutical company developing innovative immune-based biologics, has entered into a definitive license agreement with **Biogen Idec**, granting the latter exclusive worldwide rights to one of Trillium's development programs. Under the terms of the agreement, TTI will receive an upfront payment and is eligible to receive milestone payments based on achievements of specified clinical, regulatory and commercial accomplishments. TTI will also receive royalties on global product sales. Biogen Idec will be solely responsible for clinical development, regulatory approvals, manufacturing and commercialization. ■

Research

H1N1 Infection and Autoimmunity?

Individuals who develop serious pneumonia from H1N1 infection may have an autoimmune disorder, according to a study reported on in the Dec. 15, 2009, edition of *Newsweek*. According to the study, the overproduction of the immune system component Interlukin 17 may be responsible for serious illness and even death. Patients who were hospitalized with H1N1 were found to have elevated levels of Interlukin 17, a substance that can cause an excess number of white blood cells to respond to lung injury caused by the H1N1 virus, which results in increased inflammation in the lungs.

"In rare instances, the virus causes lung infections requiring patients to be treated in hospital. By targeting or blocking TH17 (Interlukin 17) in the future, we could potentially reduce the amount of inflammation in the lungs and speed up recovery," says Dr. David Kelvin, head of the study in



Canada. Study authors say that possible future interventions could include a blood test to identify those who are at high risk of developing autoimmunity in the case of H1N1 infection and potentially using drugs to regulate Interlukin 17. ■

Research

Five New Genes Identified in IBD



An international research team has identified five new genes that include one involved in a biological pathway that helps drive the painful inflammation of the digestive tract that charac-

terizes childhood-onset inflammatory bowel disease (IBD). The discovery occurred during the largest, most comprehensive genetic analysis of childhood-onset IBD, which tends to be more severe than adult-onset IBD.

Researchers at the Center for Applied Genomics at The Children's Hospital of Philadelphia performed a genome-wide association study on DNA from more than 3,400 children and adolescents with IBD, plus nearly 12,000 genetically matched control subjects. A genome-wide association study uses automated genotyping tools to scan the entire human genome, seeking gene variants that contribute to disease risk. The study identified five new gene regions that raise the risk of early-onset IBD on chromosomes 16, 22, 10, 2 and 19.

The most significant finding was at chromosome locus 16p11, which contains the IL27 gene that carries the code for a cytokine, or signaling protein, also called IL27. "This cytokine acts on a biological pathway, the T-helper 17 pathway, which plays a key role in causing intestinal inflammation," said Hakon Hakonarson, MD, PhD, director of the Center for Applied Genomics. T-helper 17 cells are recently discovered cells that lead to severe inflammation and tissue injury in autoimmune disease.

The study, which appears in the Nov. 15, 2009, online issue of *Nature Genetics*, may provide a basis for developing drugs that target the cytokine IL27's action for patients with the disease-causing IL27 gene variant. ■

Research

Genetic Clue May Predict Severity of MS

Scientists have recently identified a biomarker that may predict the severity of multiple sclerosis (MS). In a study published in *Nature Immunology*, researchers identified short RNA molecules, known as microRNAs, that were linked to MS symptoms in mice, depending on and correlated to their level of activity or expression. They found that when expression of the microRNA called miR-326 was silenced, MS severity in mice was mild. However, when expression was increased, the disease was severe.

Researchers also found that miR-326 is associated with severity

of MS in humans. The biomarker miR-326 expression was much higher in immune cells of MS patients compared with patients with a different neurological disease that affects myelin. The biomarker appears to correlate with the severity of MS by affecting the production of certain inflammatory proteins. MS is an autoimmune disease in which the immune system attacks the protective myelin sheath around nerve fibers.

It is hoped that learning how to manipulate these microRNA molecules in humans will eventually help diagnose and treat MS. ■

Did You Know?

With autoimmune diseases striking women three times more than men, a new report titled Medicines in Development: Women 2009 was released in October by Pharmaceutical Research and Manufacturers of America (PhRMA). The report lists 969 new medicines in development, including 112 new treatments for breast cancer, 86 new treatments for obstetric/gynecologic conditions, 76 for asthma, 114 for autoimmune diseases, 155 for diabetes, 131 for arthritis and 80 for Alzheimer's disease.

Grants

Patient Organizations Eligible for Advocacy Grants

CSL Behring, a global leader in the plasma-protein biotherapies industry, will award its fifth round of LEAD (Local Empowerment for Advocacy Development) grants in 2010. LEAD grants support grass-roots advocacy efforts by organizations committed to helping people who use plasma-derived or recombinant therapies to manage their health conditions. The deadline to apply for the 2010 grants is April 30.

Since the LEAD program's inception

in 2008, CSL Behring has awarded more than \$340,000 in four semi-annual grant cycles. The 2009 grants were awarded to the National Hemophilia Foundation, Advocacy for Patients with Chronic Illness Inc., Hemophilia and Bleeding Disorders of Alabama and Great Lakes Hemophilia. The 2010 grants will be awarded in June. Applications, specific criteria for applying and more information about the LEAD program can be found at www.cslbehring.com/leadgrants. ■

Research

New Genes that Cause Lupus Identified

Chinese researchers have identified several new genes that play an



important role in the development of systemic lupus erythematosus (SLE). Published in *Nature Genetics*, the study, which involved more than 12,000 samples of Chinese people, found strong associations within five genes — ETS1, IKZF1, RASGRP3, SLC15A4 and TNIP1 — and four other regions of the human genome. All five genes are involved in immune response, which the researchers say can help explain the development of SLE. The study also confirmed seven other genes previously reported in European populations.

SLE is a chronic autoimmune connective tissue disease that can affect any part of the body and impairs the quality of life of patients. It is found predominantly in women (nine times more often than in men), particularly during childbearing years. ■

Meetings

First CIS PIDD Conference Scheduled for May



The Clinical Immunology Society's (CIS) First North American Primary Immune Deficiency National Conference will be held May 20-23 in Philadelphia, Pa., in conjunction with its First CIS Annual Meeting. The primary goals of the national conference are to present the newest immune deficiency diseases and the nature of these defects in molecular terms, to serve as an interactive forum for workshops on state-of-the-art diagnosis and clinical care, and to grow the community of physicians and scientists who are working in this area. Sessions will be designed to provide stimulating discussions of immune deficiency disease issues, while delving into unsolved questions. More information about the conference can be found at www.clinimmsoc.org/meetings/2010/piddnc or by contacting the CIS at (414) 224-8095 or info@clinimmsoc.org. ■

Did You Know?

It's possible to prevent rabies if immunization is given within two days of a bite. To date, no one in the United States has developed rabies when given the vaccine promptly and appropriately.

Research

Efficacy of Flu Vaccine Reduced for Some RA Patients



According to a recent study, the influenza vaccine is ineffective for rheumatoid arthritis (RA) patients in the first six months following rituximab treatment, and only partially protects those patients six to 10

months following rituximab treatment. However, previous influenza vaccination in rituximab-treated patients does increase pre- and post-vaccination titers, which can provide some defense against influenza strains.

The study, which was published in the January 2010 issue of *Arthritis & Rheumatism*, was the largest to date of the effectiveness of the flu vaccine in RA patients using rituximab. Three groups of patients were enrolled in the study: 23 RA patients using rituximab, 20 RA patients taking methotrexate (MTX) and 29 healthy individuals. Patients taking rituximab were split into two groups with 11 who received the influenza vaccine four to eight weeks after treatment with rituximab (early rituximab sub-

group) and 12 individuals who were given the flu shot six to 10 months post-treatment with the drug (late rituximab subgroup). Influenza vaccines were administered intramuscularly between October 2007 and January 2008.

Researchers tested geometric mean titers (GMTs) for each group and found they significantly increased for all influenza strains in the MTX-treated group and in healthy controls. However, GMTs did not increase for any of the influenza strains in the rituximab-treated group. But, for the late rituximab subgroup, a rise in GMT was noted for the A/H3N2 and seasonal A/H1N1 flu strains, indicating some recovery of an immune response six to 10 months after treatment by rituximab. ■

Grants

Lupus Foundation Funds Research Grants

The Lupus Foundation of America (LFA) announced it has new funding for research grants to address issues of critical importance for people with lupus, including managing the disease in children and teens, improving health outcomes, identifying the underlying genetic causes of male lupus, facilitating greater accuracy in the diagnosis of lupus, and developing new, safe and effective treatments. In addition, the LFA has awarded five student fellowships to foster an interest in lupus research and renewed funding for the Lupus Biomarkers Clinical Consortium, a collaborative initiative that seeks to identify

biomarkers that hold promise to facilitate the diagnosis and treatment of lupus.

The LFA national research program, Bringing Down the Barriers, funds basic and clinical research, and focuses on areas that have been inadequately funded by the federal government, industry and other organizations. The association focuses on pediatric research through its Michael Jon Barlin Pediatric Research Program, established with the support of the Wallace H. Coulter Foundation in memory of Michael Jon Barlin, who passed away in 2006 at the age of 24 following a long battle

with lupus.

For more information about the grants, contact Maggie Maloney at (202) 349-1145 or maloney@lupus.org. ■

Did You Know?

The probability of heart damage in children with Kawasaki's disease is reduced considerably when steroids are combined with aspirin and IVIG.

— Pediatrics,
October 2009

Research

Genomic Toggle Switches Divide Autoimmune Diseases

Scientists at Stanford University School of Medicine have found that genomic switches can predispose an individual to one set of autoimmune disorders but protect the same person against another set. A study that was published online in the Dec. 24, 2009, issue of *PLoS-Genetics* provides a genetic basis for this clustering effect, while extending it to show how two such clusters tend to be mutually exclusive.

Researchers used data from several large genome-wide association studies of single nucleotide polymorphisms (SNPs), which are tiny genomic variations that constitute the genetic underpinning for inter-individual human differences, from eye color to nose shape and person-

ality quirks. From these studies, the researchers looked at about a half-dozen that had been conducted on patients with or without autoimmune diseases, including type 1 diabetes, rheumatoid arthritis, multiple sclerosis, autoimmune thyroid disease and a spinal condition called ankylosing spondylitis. Of those, they found 15 SNPs that predisposed an individual to several autoimmune diseases. But, they also found that a heightened risk of certain autoimmune diseases also reduced the risk of getting certain others. For instance, a chemical unit found at a particular SNP site shown to predispose people to multiple sclerosis also rendered them, as a group, more likely to have autoim-

mune thyroid disease, while an alternative chemical unit at the same SNP site predisposed them to rheumatoid arthritis and ankylosing spondylitis. What was intriguing was that people predisposed to one pair of diseases were protected against the other.

The researchers say that finding SNPs predisposing people to one or another cluster of autoimmune diseases may help catch the onset of a disease earlier. In addition, it might also help guide drug development. For more in-depth information about the study, go to www.medindia.net/news/Stanford-Study-Shows-Genomic-Toggle-Switches-Divide-Autoimmune-Diseases-into-Distinct-Clusters-62729-1.htm. ■

Research

Tick Saliva Protein May Treat Myasthenia Gravis

Researchers have found a protein in tick saliva that may help to limit the severity of the autoimmune disease myasthenia gravis. The study, which was conducted at Saint Louis University (SLU) and published in the *Annals of Neurology*, discovered that the rEV576 protein works as a complement inhibitor, which allows ticks to avoid setting off an immune response in the human host.

Myasthenia gravis is a disease that can leave patients weak and on breathing machines, and is caused by an overreaction of the complement system, a component of the immune system that specifically defends against parasites, bacteria and other pathogens. Researchers are hoping

that a new class called complement inhibitors will impede the complement system's misplaced response, and stop the body's defense system from attacking itself.

The rEV576 protein was tested on two groups of rats with mild and severe models of myasthenia gravis. The rats that were given the complement inhibitor rEV576 improved their health and experienced reduced weakness and weight loss.

"Complement inhibitors are a completely new class of drugs," said Henry Kaminski, MD, chair of the Department of Neurology and Psychiatry at SLU and one of the nation's leading experts on myasthenia gravis. "This one will probably



prove to be superior to what we've seen. Since complement is activated in many diseases such as Alzheimer's, stroke and rheumatoid arthritis, our studies may be important for other diseases." ■

Research

Vaccine to Improve Immune System in Newborns

University of Missouri researchers are working on a vaccine to improve infants' immune systems, which are susceptible to diseases and infections such as jaundice and E-coli, right after birth. The researchers have identified a group of depleted white blood cells that might lead to an immune-strengthening vaccine.

Specifically, they have found that newborns have an imbalance of two different groups of T-helper cells (TH cells), which are white blood cells and the main fighters in the immune system. Newborns have a large amount of TH2 cells, a group of white blood cells that mediates allergic reactions, but not enough of TH1 cells, a group of white blood cells that fights infections.

Environmental factors also affect the imbalance of these two groups of T-helper cells. The first time newborns are exposed to an antigen (a foreign substance that illicit a response in the immune system), their white blood cells are balanced. But, the second time they are exposed to the antigen, they create too much of the TH2 cells and not enough of the TH1 cells. This imbalance is what leads to possible infection and allergic reaction.

"What's happening is that the TH2 cells are killing the TH1 cells, creating the imbalance," Christine Hoeman, doctoral student at the University of Missouri School of Medicine, explains. "Once we know more about the timeline of the imbalance, we can start to

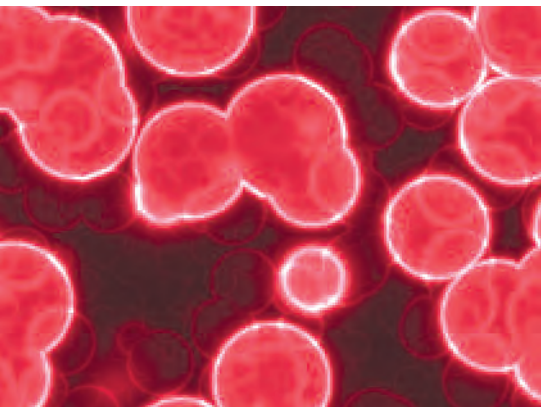


develop the vaccine, which would increase the levels of TH1 and would ideally be administered in newborns soon after they're born."

The research was published in both the *Journal of Environmental Medicine* and *Trends in Immunology*. ■

Research

New Screening for Infant Blood Disorder



A new screening program is able to identify newborns with T-cell lymphopenia, a blood disorder that affects the child's immune system, according to a study reported on in the Dec. 9, 2009, issue of *JAMA*. In the statewide study conducted in

Wisconsin, researchers examined whether determining the number of T-cell receptor excision circles (TRECs) using DNA extracted from dried blood spots on newborn blood screening (NBS) cards could detect T-cell lymphopenia. The study was conducted between Jan. 1 and Dec. 31, 2008, by the Wisconsin State Laboratory of Hygiene, which screened 71,000 infants using the TREC assay. Seventeen infants of at least 37 weeks' gestation had at least one abnormal TREC assay, 11 of whom had samples analyzed to enumerate T cells. Eight infants demonstrated T-cell lymphopenia, who were then evaluated by a clinical immunologist.

Infants with severe T-cell lym-

phopenia (abnormally low level of white blood cells), including severe combined immunodeficiency (SCID), often appear normal at birth and have no family history of immunodeficiency. "Consequently, many infants with severe T-cell deficiencies are not identified until life-threatening infections occur," the study's authors say. "This is an important issue because the long-term prognosis of infants with SCID and other serious immunodeficiencies is markedly improved if the diagnosis is made early, before the onset of serious infections." In addition, some vaccines that are recommended in early infancy can cause serious infection in infants with T-cell lymphopenia, which could be avoided with early detection. ■

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How Exercise Benefits the Immune System

Research shows 10 main ways in which exercise boosts the body's immune system to help it fight off illness.

By Matthew David Hansen, DPT, MPT, BSPTS

Many of the health benefits of exercise have been well studied and publicized. For instance, we know that different types of exercise can promote weight maintenance and muscle growth, improve respiratory endurance and cardiovascular health and increase bone density in weight-bearing joints. However, what many people don't know (or at least fail to understand) is that exercise also can improve the immune system.

Years of evidence support the claim that the right amount of certain types of physical activity can promote good health and improve symptoms in individuals with conditions of impaired immunity. Interestingly, the benefits of exercise appear to be similarly evident in persons with deficient immune systems and in persons whose systems are overly active (as is the case with autoimmune disorders). Although science still strives to better understand the exact relationship that links exercise and improved immunity, a number of theories have already been advanced.

Most people accept a few things on blind faith, but knowing how and/or why something works encourages many individuals to find a way to incorporate those things into their lives (assuming it is believed to be important). Exercise is no exception. Yet, to really understand the effects of exercise on the immune system, it's useful to first have a basic knowledge of the system itself.

The Immune System “Starting Lineup”

The immune system is an amazing and somewhat complex system, with the lymph vessels serving as its delivery (or highway) system. Lymph is a semi-clear liquid that carries needed water, oxygen and nutrients that have been transferred through the blood system (via the walls of the capillaries) to the cells themselves. Together, the lymph and lymph vessels transport uninvited guests and cell waste from the cells and their surroundings to the lymph nodes to be filtered, processed and drained. Lymph nodes are found throughout the body (including the sides of the neck) and frequently enlarge as they respond to new white blood cell production during an infection. For instance, when a person's glands are swollen, there's a good chance that his or her body is trying to fight something. Although any biologist would accuse us of oversimplifying the definitions, let's take a look at some of the major players of the immune system:

T Cells. Most of the cells that make up the immune system are white blood cells. One type of white blood cell, the lymphocytes, includes two major groups referred to as “T cells” and “B cells.” T cells have receptors on their surface that interact with molecules (i.e., small particles of a substance composed of two or more atoms) that are found on other cells of the body. By “hooking up” to the molecules, T cells can recognize the matter as something that is supposed to be in the body, or recognize it as a foreign substance or invader like a virus or bacterium. Once an invader is detected, the different types of T cells either work to directly destroy them or work to assist other immune cells in coordinating an attack.

Cytokines and Chemokines. One of the responses that T cells can mount against a trespasser is to secrete cytokines and chemokines. Cytokines are molecules that can activate other immune system cells that are nearby, or signal them to grow or to die. Chemokines are small groups of cytokines that attract more immune system cells to the area of the body where they are needed.

B Cells and Antibodies. Certain cytokines released by T cells will activate and direct another type of lymphocyte, the

B cells, to make specific antibodies (aka, immunoglobulin) against a foreign substance. Antibodies then seek the invaders and bind them to sites on their surface known as antigens. By binding to an antigen, an antibody can either neutralize the foreign object directly or mark it for destruction by other members of the immune system.

Moderate exercise improves blood flow through the cardiovascular system, thereby helping to flush toxins and germs from the body through the excretory system via urine and sweat.

Phagocytes. Phagocytes are white blood cells that are either stationary or circulate through the bloodstream and ingest harmful substances and dead or dying cells. A certain class of phagocytes, known as “professional” phagocytes (e.g., macrophages, neutrophils, monocytes, dendritic cells and mast cells), also possesses receptors on their surface (somewhat like those found on T cells). Once they have successfully engulfed a foreign invader, they will display part of its remains on their receptor and then present it to other cells of the immune system (including lymphocytes in the lymph nodes) to stimulate a larger response to the infectious agent.

Benefits of Exercise

Understanding how these players in the immune system work, let's look at 10 ways that exercise might benefit the immune system.

1. One of the most apparent benefits of light exercise is its ability to promote the flow of lymph and the immune



cells and antibodies it carries through the body. Unlike the arterial blood vessels, lymph vessels don't have the power of a pump (i.e., the heart) behind them. Instead, they depend on normal body motion, muscle contraction and manual manipulation such as massage to move the lymph along. Deep breathing with stretching (e.g., yoga or tai chi) is another effective exercise for circulating lymph.

2. Moderate exercise improves blood flow through the cardiovascular system, thereby helping to flush toxins and germs from the body through the excretory system via urine and sweat. Increased blood flow also keeps the antibodies and white blood cells needed to fight infection circulating rapidly as a possible early defense against foreign invaders.

3. When the body is deprived of sufficient oxygen as a result of high altitude, strenuous exercise, impaired breathing or other situations (a condition known as hypoxia), the immune function is impaired. Moderate exercise increases oxygen delivery through the bloodstream, thereby potentially improving the body's resistance.

4. Exercise slightly raises the body's temperature. Although the increase is not nearly as dramatic as running a fever (one of the body's natural reactions against many types of infection), it may still help to kill and/or inhibit the growth of an unwanted aggressor.

5. Scientific studies have recorded a temporary increase in phagocyte activity and function immediately following

exercise. It is believed that this increase could take some potentially harmful substances out of the bloodstream before they ever get the chance to travel further. It may also help to boost the fight against an active infection.

6. Regular exercise may help the lungs to rid themselves of airborne viruses and bacteria that are associated with respiratory tract infections.

7. A certain group of cytokines are produced as a consequence of muscle contraction during exercise. One of these cytokines, IL-6, initially promotes inflammation (an important first response of the immune system against infection), but is shortly followed by an increase in anti-inflammatory cytokines. Turning off the inflammation phase is just as important as turning it on; otherwise, tissue and organ damage can occur.

8. T1 helper cells also stimulate inflammation and other changes in the body as a first defense against infection. They are followed by T2 helper cells that produce an anti-inflammatory response. A recent study at the University of Illinois demonstrated that moderate exercise in mice appears to accelerate the change from a T1 to T2 response enough to help combat infection with the flu.

9. Another recent study conducted at Iowa State University found that mice that regularly ran on a treadmill during a period of three and a half months experienced flu symptoms that were less severe than those developed by mice that did not exercise. The study's lead researcher suggested that repeated stress from moderate exercise may improve the body's ability to respond to other types of stress, like those caused by the flu.

Even relatively low levels of aerobic exercise can help to boost the immune system.

10. Speaking of stress, one of the greatest benefits of regular exercise is its ability to help relieve mental and emotional stress linked to suppressed immunity and increased illness. Exercise helps to provide an outlet for nervous energy, take our mind off of our greatest concerns (at least momentarily) and improve our body image. It also

reduces the emission of stress-related hormones long thought to suppress the immune system.

Putting Science Into Action

The 1st century Roman philosopher Marcus Cicero declared, “Never go to excess, but let moderation be your guide.” These words should be applied prudently toward many aspects of our lives: eating, drinking, sleeping, working, playing — and exercising! Note that the key to the positive outcomes observed in many of the theories and research listed above is “regular and moderate exercise.” In fact, many studies assert that high-intensity or strenuous exercise can actually cause a temporary decrease in the immune system’s defenses, referred to as an “open window” period, which can last anywhere from three to 72 hours following the activity. Arduous exercise may also exacerbate other symptoms with autoimmune diseases. Of course, exercising too little or not at all can be just as detrimental to an individual’s health.

So, how much exercise is just the right amount? The answer, of course, varies somewhat among individuals, and a doctor should always be consulted first before beginning a new program or before making any major changes to a routine exercise program. However, even relatively low levels of aerobic exercise can help to boost the immune system. Generally speaking, 20 to 30 minutes of a low-impact activity (e.g., brisk walking, light jogging, swimming or biking), three to five times a week, is a great place to start. Regular moderate exercise appears to have a cumulative effect that leads to a more permanently improved immune response, and again, the benefits seem to be accessible to nearly everyone, regardless of their personal immune status or history.

Several other factors can contribute considerably to the effects of exercise on the immune system and should be considered when planning activities. For example:

- Exercise is discouraged in extreme heat or cold because the changes that are required to help regulate the body’s temperature can be stressful to the immune response. Those who live in a cool climate during the winter months should plan more indoor activities like swimming, stationary biking, or walking or jogging on a treadmill (good sanitation techniques should be used when using public facilities). Those who live in a hot climate should try to arrange outdoor physical activities earlier in the morning or later in the evening to escape the heat of the day.
- Exercising at especially high altitudes or in areas of high air pollution should be avoided, because both situations

can stress the respiratory system and, in turn, the immune system due to decreased oxygen in the air.

- Finally, individuals who aren’t feeling well need to be honest with themselves. When ill, the immune system is already under strain from trying to fight the infection. The related stress caused by exercise may challenge recovery. However, for individuals who feel like they are just coming down with something, symptoms are mild and they don’t have a fever, there is evidence to suggest that moderate exercise might actually decrease the duration and severity of a mild infection (a doctor should always be consulted for direction).



Remember that there are many benefits of exercise besides those immediately related to an improved immune system. If 20 to 30 minutes of walking is beyond an individual’s current ability, there is always something that can be done (see the article, “Exercise and Immune Disease” in the December-January 2010 issue of *IG Living* magazine). The body’s little friends are working hard to maintain well-being — and sending them a big breath of fresh oxygen can only help. ■

MATTHEW DAVID HANSEN, DPT, MPT, BSPTS, is a practicing physical therapist in Utah, and president of a healthcare consulting and fitness product company, SOMA Health, LLC. The company’s latest product, the Freedom2Move exercise program and video series, was inspired by an *IG Living* Readers Teleconference. Matt completed his formal education at the University of Utah in Salt Lake City.

Understanding and Treating IG Side Effects

Knowing what side effects, from mild to serious, to expect during and after immune globulin infusions can prepare patients and their caregivers for treatment changes to mitigate their impact.

By Ronale Tucker Rhodes, MS,
and Kris McFalls



It makes most people chuckle: A television commercial touts the benefits of a wondrous new drug; the patient is smiling and laughing, obviously enjoying a newfound healthy lifestyle while spending time with family and friends. Then, the announcement: "Side effects include ..." Wow, the viewer thinks, no thanks!

The truth is that there is nothing funny about a drug's side effects — especially when it comes to a life-sustaining drug like immune globulin (IG). IG patients either undergo the treatments or they forgo them, which brings on far worse consequences than those caused by side effects. Fortunately, many IG patients never experience any effects, and while those who do often think they are having a severe reaction, by definition, the reaction is typically a moderate or mild side effect. And, the good news is that in almost all cases, the effects can be controlled or even eliminated.

Side Effects Defined

Side effects, also referred to as adverse drug reactions (and considered one and the same by the Federal Drug Administration [FDA]), are those that are expected, although undesired, and are listed on the package insert for each medication. Mild or moderate side effects typically occur due to the manner in which the treatment is administered, and they can be managed. Serious side effects, on the other hand, also can be a result of the components of the drug itself and result in hospitalization or prolongation of an existing hospitalization and can be life-threatening.

The Mayo Clinic has an exhaustive list of side effects available at www.mayoclinic.com/health/drug-information/DR601705/DSECTION=side-effects. Most of these effects often can be eliminated by stopping the infusion temporarily and then restarting at a lower infusion rate, and even by switching the treatment modality.

Mild and Moderate Side Effects and Treatments

Mild and moderate side effects of intravenous IG (IVIG) are headache, flushing, chills, myalgia, wheezing, tachycardia, lower back pain, nausea and hypotension. Headaches and their more severe form, migraines, tend to be one of the more common side effects. Patients can overcome both forms of headaches by treating with antihistamines, NSAIDs and steroids both before and after an infusion. In addition, hydrating before, during and after an infusion can help alleviate these discomforts.

Other forms of treatment also can be tried. For example, a patient just beginning IVIG treatments experienced a mild migraine the day following her first treatment. As a further preventative, she increased hydration and took Tylenol before her next two treatments. Regardless, on her third treatment, she experienced a severe migraine lasting three days. For her next infusion, her doctor

ordered a small dose of prednisone to be taken the day before the infusion, the day of the infusion and the day after the infusion. In addition, the rate of the infusion was decreased. With these treatment adjustments, the patient still experienced occasional mild headaches, but she no longer had migraines.

In another instance, a patient experienced severe migraines following IVIG infusions. The patient was given Tylenol, Benadryl and steroids, as well as a migraine prophylaxis, prior to treatment, but the headache symptoms persisted. Different formulations of IVIG 5% and 10% were then tried, but the migraines continued. So, the patient switched to subcutaneous IG (SCIG), which has eliminated the problem, and no premedications are needed.

Mild or moderate side effects typically occur due to the manner in which the treatment is administered and can be managed.

For SCIG patients, the most common side effects include headaches and local irritation (redness, swelling, itching, blanching) at the needle site. Some reactions, especially for patients new to SCIG therapy, are expected, and most decrease with time once the body becomes accustomed to the therapy. For patients bothered by reactions, applying ice or heat to the needle sites can help decrease some of the symptoms. Using a topical anesthetic cream 30 to 60 minutes prior to starting the infusion also can be helpful. Patients with persistent symptoms should explore needle placement as a possible cause. If the needle is not properly placed, it is possible that some of the fluid is leaking into surrounding tissue rather than into the subcutaneous space. A provider experienced in SCIG therapy should be able to help patients troubleshoot and eliminate possible causes to site reactions. However, in some cases, patients are simply unable to tolerate the side effects of SCIG and need to switch back to IVIG treatment.

Serious Side Effects and Treatments

Serious side effects are rare, and most can be reduced by screening the patient for factors predisposing them to complications.² Serious side effects can include acute renal failure, thrombosis, Stevens-Johnson syndrome, serum sickness, aseptic meningitis and anaphylaxis. The most severe form of IG-related headache comes from aseptic meningitis, and in fact, patients with a history of migraines appear to be more susceptible to aseptic meningitis. Symptoms, which are severe and similar to meningitis, usually begin a few hours after treatment but can occur up to two days later. They can include severe headache, photo sensitivity, chills, nausea, vomiting, fever and painful eye movement. Although cerebrospinal fluid (CSF) can show increased white blood cells and proteins, cultures are generally negative, thus resulting in the aseptic diagnosis.¹ Treatment to prevent aseptic meningitis includes antihistamines, NSAIDs and steroids both before and after an infusion.

Anaphylaxis, a rapidly progressing, life-threatening allergic reaction, can be a side effect of both IVIG and SCIG. Anaphylactic reactions may require administration of corticosteroids and antihistamines, and in very severe cases, administration of epinephrine.³

Serious side effects are rare, and most can be reduced by screening the patient for factors predisposing them to complications.

A case in point: One patient who experienced anaphylaxis is a child named Julia. At 7 months old, Julia was diagnosed with pertussis, despite having been vaccinated. Julia's health deteriorated so rapidly that she was sent by ambulance to a hospital where she stayed for nearly three weeks. At age 5, she was diagnosed with a primary immune deficiency, and at age 6, IVIG treatments were



started. Unfortunately, her infusion days rarely went smoothly. From the beginning, Julia was plagued with flu-like symptoms, and by age 9, she experienced severe migraines lasting three days. Doctors treated Julia with Benadryl and prednisone prior to her infusions, as well as with intravenous Benadryl during her infusions. In addition, the rate of infusions was slowed down so much that they took eight hours to complete.

When she turned 10, Julia's doctors decided to try another brand of immune globulin, hoping to shorten infusion time and decrease side effects. Unfortunately, Julia's side effects worsened. During the infusion, Julia felt her chest tightening and told her mother she was having trouble breathing. Overcome by an anaphylactoid reaction, Julia went into respiratory arrest, so the doctors quickly stopped the infusion and administered valium and epinephrine. At this point, Julia's parents considered halting all treatments; it seemed their daughter's life was threatened with or without IG. But, after weighing the risks and benefits, doctors successfully resumed therapy with the original brand of IVIG. When Julia was 13, doctors suggested subcutaneous infusions in hopes of giving Julia her life-saving IG without risking her life. This worked; Julia was soon free of the side effects that plagued her with every treatment.

Anaphylactic and anaphylactoid reactions (both referred to as anaphylaxis) are life-threatening events that

result from an overreactive and misdirected immune response to a substance that is viewed by the body as foreign (an antigen). An anaphylactic reaction is an acute fatal, or potentially fatal, hypersensitivity reaction that requires the patient to be sensitized and their reaction mediated through immunoglobulin E (IgE) antibodies. An anaphylactoid reaction doesn't need the presence of IgE antibodies for a hypersensitivity reaction to occur. Thus, an anaphylactic reaction occurs only after the patient has been previously exposed at least once to the antigen and is sensitized. And, it can occur following a single, first-time exposure to certain agents in nonsensitized patients.⁴

Anaphylactic and anaphylactoid reactions to IVIG therapy are relatively rare, but they can occur in any patient at any time. Some IgA-deficient patients produce certain IgA antibodies that can increase the potential for anaphylaxis. For those patients, it is prudent to use an IVIG product that has a very low IgA content. Alternatively, many patients who experience anaphylaxis have had good success by switching their route of infusion from intravenous to subcutaneous.⁴

Anaphylactic and anaphylactoid reactions to IVIG therapy are relatively rare, but they can occur in any patient at any time.

Documenting and Reporting Side Effects

Both the FDA and European regulatory authorities are encouraging patients and healthcare professionals to report adverse drug reactions so that any unknown serious side effects, such as those that occurred with Vioxx, can be discovered more quickly. (Vioxx and related pain medications were taken off the market in 2004 because they caused dangerous heart problems in some people.)

The purpose of documenting and reporting these effects is to prevent future injuries for patients. Of particular importance to the FDA are suspected adverse drug reactions for a new drug (i.e., within three years of entry to market) and suspected severe adverse drug reactions for any drug, no matter when the drug entered the market.⁵

The FDA also requires many manufacturers of newly licensed drugs to perform post-marketing risk management (pharmacovigilance studies) to collect information on adverse reactions in a more proactive manner. Additional information on serious adverse drug reactions and instructions for reporting an adverse drug reaction to the FDA can be obtained at www.fda.gov/Safety/MedWatch/HowToReport/default.htm.

Benefits Outweigh Risks

IG is one of the safest biological products available, and although severe side effects have been reported, they are rare. The good news is that almost all side effects can be safely controlled and often eliminated altogether. And, with the growing number of diseases being treated today with IG, as well as the stringent testing and reporting standards mandated by the FDA, patients who rely on this life-saving treatment can rest assured that they can be safely treated. ■

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RONALE TUCKER RHODES, MS, is the editor of IG Living magazine, and **KRIS MCFALLS** is the full-time patient advocate for IG Living magazine, written for patients who depend upon immune globulin products and their healthcare providers.



How to Handle Insurance Disputes



By responding appropriately, patients often can get their insurance claim denials overturned in their favor.

By Jennifer C. Jaff, Esq.

Individuals who have health insurance often face obstacles to obtaining the healthcare they need. Unfortunately, those obstacles increase for patients with a chronic illness. In fact, it is a rare occasion when patients with a chronic illness do not have to fight with their insurance company over something such as a medication, hospitalization or a diagnostic test. And, while most patients don't know where to begin when faced with an insurer's non-coverage decision, responding appropriately will help to ensure the outcome is in their favor.

What Not to Do

Patients should understand that there are some hard-and-fast don't-do rules. First, patients should never call an insurance company to appeal a denial of coverage. If insurance company representatives review what is already on file, it is highly unlikely that their opinion will change. To change their decision, something new has to be submitted.

Nor should patients hastily submit a letter that says, "But my doctor says I need this." The insurance company denied coverage after the doctor ordered the item or service in question. Therefore, they already know the doctor thinks the patient needs it; they disagree.

So, prior to responding to the insurance company's denial, patients need to determine why coverage was denied. This, then, will determine how they should respond.

Countering Claim Denials

If a claim denial is due to an alleged lack of medical necessity, patients must prove that the item in question is medically necessary. This will require patients to compile medical records, and send them with a detailed letter to the insurance company, that establishes the diagnosis, lists

If a claim denial is due to an alleged lack of medical necessity, patients must prove that the item in question is medically necessary.

the treatments that have been tried and failed, and outlines the reasons their doctor believes this item is medically necessary. Medical necessity is best established with a short letter from the doctor, which should accompany the patient's letter and records.

If a denial is due to the insurer's belief that the item or service is experimental or investigational, patients will need to take one additional step to prove that, in addition



to being medically necessary, the item or service has been tried, tested and vetted in published medical journal articles. If possible, patients should try to get their doctor to help with this, as it can be hard to obtain copies of medical journal articles without going to a medical school library. Another option is to locate summaries of articles on the Internet at websites like PubMed (www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed) or search engines like Google Scholar (scholar.google.com).

There also can be countless other reasons why insurance coverage is denied, and for each reason, patients need to tailor their response to effectively counter the insurance company's reasoning. For example, in some instances, doctors' offices make coding errors, which need to be corrected with the individual in charge of billing. In other instances, insurers receive bills without any supporting documentation, and patients will need to provide those documents. Whatever the reason, patients' appeals should respond to the specific reason for denial.

Insurance denial also may be a result of whether the request for coverage comes prior to or after treatment. These days, patients must get prior authorization from their insurance company for most expensive tests and treatments. If an insurer denies prior authorization, patients must appeal and obtain a favorable decision prior to having the test or treatment. If they don't, failure to get prior authorization is itself a reason for denying coverage.

Filing an Appeal

When filing an appeal, patients must ensure that they meet the deadline. Most insurance policies require the first-level appeal be submitted within 180 days of the date of the denial letter. Subsequent levels of appeal typically are required to be filed in an even shorter time frame. If appeal deadlines are missed, in most cases, patients have no recourse at all.

Depending on the type of insurance, it may be possible to file an appeal with an external reviewer after exhausting appeals to the insurance company. There are two types of insurance: fully-funded and self-funded. All individual health insurance plans, most small group plans and many large group plans are fully-funded plans, which means the individual or their employer pays a premium and the insurance company pays for the healthcare. However, some large group plans are self-funded plans, in which the employer pays a third-party administrator (TPA) to administer the plan and the employer pays for the healthcare. Self-funded plans are governed by the federal law known as ERISA, the Employee Retirement Income Security Act.

When filing an appeal, patients must ensure that they meet the deadline.

Most states have enacted laws that provide for a review of insurance company denials of coverage by an external reviewer independent of the insurance company. As a result, after exhausting appeals to the insurance company, patients have the right to one more appeal, usually through their state insurance department. However, because these “external appeals” are created by state law, they do not exist for self-funded plans — unless the plan itself requires it, and some do. For example, in a large corporation like General Motors, although the insurance plan is self-funded, it provides for external, independent reviews of insurance company decisions. The same is true of the federal employee plans, which allow an

independent review by the United States Office of Policy Management.

External appeals — whether the plan is fully-funded or self-funded — are the most important consumer protection to have been developed in the insurance arena. It's not uncommon for insurance companies' denials of coverage to be overturned following an external appeal. Indeed, some insurance companies' decisions are regularly overturned after an external appeal.

Going to court is the sole recourse for patients who are in self-funded plans that do not provide for an independent review. In fact, if patients receive a denial letter specifying they have a right to file a civil action under section 502(a) of ERISA, that means their efforts to resolve the dispute without going to court have been exhausted. Therefore, to pursue the matter further, they will need to hire an attorney who handles ERISA cases.

However, going to court is not a good option in most instances. In fact, it's rare to find an attorney who will take an insurance claims case on a contingency basis, which means one-third of what the patient ultimately wins will go to legal fees. This is because most insurance claims — even high-dollar ones — do not result in large enough settlements to cover the lawyer's time and expense (unless the settlement is greater than \$50,000). Therefore, in most cases involving health insurance claims, patients will have to pay a lawyer on an hourly basis.

Going to court in an ERISA case also is particularly difficult. In ERISA cases, courts give deference to insurance company decisions unless there has been a serious procedural irregularity or conflict of interest. In addition, no new evidence can be presented in court; the evidence is limited to what has been submitted to the insurance company — all the more reason to take the initial insurance appeals seriously.

You Can Win

Thankfully, though, most of the time, patients don't need a lawyer to win an insurance dispute. They just have to take it seriously, take their time, gather medical records and other materials, and address the reasons why their claim was denied. ■

JENNIFER 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.

Ask Kris

By Kris McFalls

Have a question? Kris McFalls, *IG Living's* patient advocate, is eager to find answers. Email them to editor@IGLiving.com. Your confidential information will not be used for any purpose but to communicate with you about your questions.

Sally: I have two children, one of whom has common variable immune deficiency (CVID). I have been advised not to have my child with CVID vaccinated with a live vaccine. However, I need to have my other child vaccinated, and I worry about the potential risk of exposing my CVID child to a live virus. Are there any precautions I should take?

Kris: Sally, your concern is common among parents of kids with a primary immune deficiency disease (PIDD). I have asked Dr. Richard Schiff to address your questions.

Dr. Schiff: The risk of exposure to a live vaccine depends on the disease. In general, a CVID patient on intravenous immune globulin (IVIG) should be protected from any of the live virus vaccines, other than rotovirus. Although it hasn't been studied, there is not a lot of circulating antibody to rotovirus, so I doubt that IVIG has enough antibody to be protective. The real risk, beyond rotovirus, is to those patients with T cell disorders, but even they should be protected by IVIG.

In general, a sibling of a PIDD patient can be immunized with a live virus vaccine other than rotovirus. However, ideally (although not necessarily required), the sibling should be isolated from the PIDD patient for the first 7 to 10 days while they are the most infectious. Until more information is available, the rotovirus vaccine should be avoided. However, if a sibling is immunized with the live rotovirus vaccine, it is important that the PIDD

patient has adequate levels of antibody so that they will be protected, and the patient and sibling should be separated for at least 10 to 14 days.

Reader: I'm a mother of two kids and was diagnosed three years ago with common variable immune deficiency (CVID) after suffering from sinus infections for many years. I'm fortunate that I did not suffer from the respiratory ailments of other CVID patients. Since I began receiving intravenous immune globulin (IVIG), I now have very few sinus infections and lead a very healthy life. Because I've been so healthy since starting the treatments, I was shocked to receive a letter from my life insurance company stating that I've been declined coverage because I am receiving IVIG. Is it common to be declined coverage when you are an IVIG patient?

Kris: In a discussion with this reader, I learned that she was trying to access a higher value of insurance through her employer-sponsored program. To gain some insight into this situation, I spoke with a healthcare attorney who happens to have CVID. Speaking from his personal experience and not from his professional experience, he speculated that it is possible the life insurance company that sponsors the employer's plan has a value limit. When you cross that limit, you are required to answer some health questions, which can

then constitute grounds for denial.

Once you have been denied life insurance, in the future, you will always have to check the box on life insurance applications that states you have been denied. That box is a red flag for more scrutiny. However, you can look into the possibility of getting life insurance without having to submit an application. Giving your file without identification to a broker and requesting the broker do a dry run, so to speak, can give you answers before filling out a formal application. However, having a positive response with a generic file does not guarantee the same outcome when the application is submitted with your name on it.

In discussing your situation with a human resource manager, I learned that indeed there is a ceiling on the amount of life insurance you can get without having to fill out a questionnaire. The amount varies depending on employer-held contracts. To find out what your limit is, check with a human resource representative at your place of employment. ■



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

Richard Schiff, MD, PhD, is global medical director in the department of immune therapy at Baxter BioScience.

Let's Talk!

By Trudie Mitschang

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.



month, we chat with Coni Dutka, a plasma donor who has discovered that donating plasma is life-changing — for the donor, as well as the recipient.

Coni describes herself as someone who always had a drive to make the world a better place. A retired educator who devoted her life to serving children and families, Coni also spent many years volunteering as a blood donor. But it wasn't until about a year ago when her niece introduced her to the idea of plasma donation that Coni found her new life's calling.

not far from my home. I went there, met other donors and met the staff. It felt like a family there; everyone was clearly passionate about their mission, and I knew I wanted to be a part of it.

Trudie: How do you prepare for a draw?

That's when I realized that donating plasma is similar to donating an organ because something from my body is going into someone else's body and giving them life.

Plasma is sometimes referred to as the "gift of life" because it is so essential to the various therapies that help thousands of people living with rare, chronic diseases to have healthier, more normal lives. And while plasma donors are paid for their services, not everyone who gives of their time and blood in this way is motivated by financial gain. This

Trudie: Tell me how you became a plasma donor.

Coni: After my niece told me about donating plasma, I went online and did some research. I landed on a website for Talecris and was very impressed with the company and what they did. Later, I learned there was a Talecris plasma donation center

Coni: You start preparing a couple of days before your scheduled appointment by maintaining a good level of hydration, drinking lots of water and getting adequate protein consumption and rest. The day

before my draw, I make sure I drink 80 ounces of water; the more fluid you consume, the better the draw will be. The day of the draw, I eat well two hours before and take a snack with me in case I have to wait.

Trudie: How are plasma donors screened?

Coni: Before you can donate, you have to have a physical that they perform at the center, and then you undergo an intensive screening each time you come in. They check my blood pressure, pulse, temperature, weight and my red cell count. They want to make sure that I am healthy to donate each time I come in. They also ask several questions to ensure that my activities or behavior would not prevent me from donating.

Before you can donate, you have to have a physical that they perform at the center, and then you undergo an intensive screening each time you come in.

Trudie: How long does it take to complete a draw?

Coni: For me, it's usually less than an hour depending upon how hydrated I am. They have a TV in the donor

room, or you can just read. When you're done, they usually give you a sports drink and encourage you to go home and have a good meal.

Trudie: What do you find most rewarding about being a plasma donor?

Coni: I had the opportunity to go to Raleigh, N.C., and tour the Talecris headquarters. I was amazed watching the detailed fractionation process. Seeing what happened after I donated was very impressive. But then I had the opportunity to meet some of the patients and their caregivers. That experience changed my life. That's when I realized that donating plasma is similar to donating an organ because something from my body is going into someone else's body and giving them life. When you encounter someone you don't know who is alive because of you — that's huge.

Trudie: What would you say to someone considering plasma donation?

Coni: I'd say don't wait until you are as old as I am. The cutoff age for plasma donation is 65, so I only have one more year, but I know I will still be involved in some way. To me, this is the ultimate random act of kindness. You are doing something simple, yet profound that will change the lives of many people. ■



Coni and her four grandgirls!



TRUDIE MITSCHANG is a staff writer for IG Living magazine.

Transitions

By Ronale Tucker Rhodes, MS

Immune globulin (IG) is a miraculous therapy, and no one knows this better than patients who receive it for an immune-mediated disease. Indeed, without IG, these individuals would fail to make the transition from living in a constant state of illness, struggling to survive, to a healthy, happy lifestyle. That is what this column is about — the unique and sometimes extraordinary stories of people of all ages whose lives have positively transitioned with the help of IG. We want to hear your stories! Email us at editor@igliving.com.

Meet Branson Worthen

UNFORTUNATELY, IT'S NOT SUCH an unusual story: A child is repeatedly hospitalized due to infection and fails to develop as others in their age range, yet for years, despite desperate searches for answers, no doctors are able to determine the problem. It's a common nightmare for many parents whose children are eventually diagnosed with an immune deficiency disease. One Roger and Connie Worthen experienced, but, today, until you hear their son Branson's story, you'd never know what adversity they had overcome.

An Adolescent Roller Coaster

Branson was born six and a half



Branson, born with CVID that was undiagnosed until age 5, visited FFF Enterprises to explain how IVIG, and now SCIG, has changed his life.

weeks premature in 1991. But being premature didn't begin to describe what Branson would eventually face as an adolescent. According to his mother, Connie, Branson wasn't growing like other toddler children. In addition, he was constantly sick, yet never had a fever, and he was always on antibiotics. They went to see doctors, including a growth specialist. At 2 years old, Branson was diagnosed with celiac disease, his first diagnosis. Then, other doctors speculated he might have muscular dystrophy, among other diseases.

At 5 years old, on Christmas Day,

Branson failed to wake up. When his parents went to check on him, they discovered he had an alarming

*Branson's life
forever changed
with IVIG.*

fever of 106 degrees Fahrenheit. The next day, his general practitioner diagnosed him with scarlet fever, and even when he was treated

for it, Branson was unable to fight off the infection. Finally, he was referred to an immunologist who correctly diagnosed him with common variable immune deficiency (CVID). His IgG levels were tested and found to be at around 200, whereas normal IgG levels are in the 700-plus range. And, although it took six months to finally get it, Branson was started on a treatment of intravenous IG (IVIG).

Life-Changing Therapy

Branson's life forever changed with IVIG. He lettered in swimming four years in high school and worked at a Boy Scout camp during the summers for five years (with his IVIG shipped directly to the camp). Today, at age 18, he is an Eagle Scout with four palms (meaning he has 42 merit badges)



Branson demonstrates how he self-infuses SCIG, a transition he made from IVIG in 2007.

and works as a lifeguard in his home state of Utah.

Two and a half years ago, Branson decided to transition to subcutaneous IG (SCIG) — no small feat for anyone, much less a teen. While he

proactive approach to helping others as a way of thanking those who have helped him. In 2008, he attended the Painted Turtle camp (a Hole in the Wall camp funded by Paul Newman). While there, he

Branson's positive attitude is no doubt a byproduct of his parents' outlook.

struggled with the self-infusion process the first couple of months (one day, he sat for 45 minutes before getting up the nerve), he is now successfully infusing SCIG on a weekly basis, using two 6 mm needles (since he is so thin), which takes about 3-1/2 hours to complete. This successful transition has made it possible for him to plan for his upcoming two-year mission for his church. "Because of these meds, I am able to live my life to the fullest," Branson says. "I'm able to lead a normal life. I just have to be careful. We use a lot of sanitizer. And we drink a lot of OJ."

Branson's positive attitude is no doubt a byproduct of his parents' outlook. According to his father, Roger, they decided early on that the family needed to take a proactive approach. They needed to figure out what they could do to make living with CVID better for Branson and the family. Branson has two brothers who are equally supportive, and since 1999, he has had a companion dog to help him maintain that positive attitude.

Branson has now turned that

mentored a 12-year-old girl who had just started on SCIG, but as Branson explains, "she just couldn't handle it." Branson coached her by demonstrating his own self-infusion techniques, and the girl was able to start self-infusing on her own within a few weeks.

"Paying it forward" is a guiding principle that Branson has learned from the approximately 500 plasma donors it takes to produce just one of his 52 infusions per year. To show his appreciation for their service, he regularly visits plasma centers to talk with donors and model as living proof of the good they are doing.

A Transitional Transformation

While Branson's story is a happy one and he is living his life to the fullest extent possible given his diagnosis of CVID, he still suffers from chronic sinus infections. But, as he emphasizes, he's not in the hospital. And, this could only be made possible with IG, a miraculous therapy. ■

RONALE TUCKER RHODES, MS, is the editor of IG Living magazine.

“Momma, You Got Some ‘Splainin’ to Do!”



By Cheryl L. Haggard

MY HUSBAND, MARK, and I were in hopes that because of our kids’ primary immune deficiency disease (PIDD), they would be more aware of their bodies and how they work. I have to admit I’ve learned more

than I ever thought possible about the human body since my own diagnosis. As for our kids, they grew up in doctors’ offices and hospitals, peppering the medical staff with questions like “What does that bone

do?” or “Does everybody have a thing like that?” And, if our physician was running behind, we’d come up with time-killing games like “Pin the Tympanic Membrane in the Ear Canal,” or “Tic-Tac-Where’s-Your-Toe?”

Those innocent days are long gone, as a “tween” now resides among us. Mark and I thought we were entering this season with sex education skills. We watched the school’s sixth-grade video with other freaked-out parents of 12- to 13-year-olds and thought our past medical experiences with the kids qualified us as pubescence pros. I mean, I wasn’t about to lock Calvin in a cafegymatorium with his fellow middle-school mates, leaving him in the hands of a public health nurse who is armed with pamphlets and photos to explain the “birds and bees” (while I and my gal pals go cry in our lattes — like some moms I know).

Yes, I was ready for the “Big S,” the “Where do babies come from?” or “Why do I have a belly button?” question. I was prepared to field *the* question with the seasoned savvy of a PIDD parent pro.

Until I was folding laundry one day.

“Mom, what’s sex?” Calvin asked me randomly as I exited my safe hiding place (my bathroom).

I stared blankly at my son, acting as if I was struck suddenly by an imaginary lightning bolt (Just hoping!).

“Er, um, did you say something, Calvin?” I asked, my lower lip quivering.

The hormonal Haggard walked closer to me, his sea green eyes begging for an answer to the question I knew was coming. But, did he have to ask me on laundry day? Why today? Where’s my husband? Isn’t this something for a father and son to discuss? I want my mommy!

Snapping to, I tried thinking back to the silly sixth-grade video, wondering where my so-called confidence disappeared.

“Mom? You OK?” Calvin asked,

placing his warm hand on my shuddering shoulder.

“Uh, yeah. I’m OK, I’m just, well ... ”

“Nervous?” Calvin asked, putting a halt to my jibber jabbering. “It’s OK, Mom. Mr. Harris said you might be a little dazed by me asking you about sex.”

Ugh! He said it again, I thought, wondering if I should wash his mouth out with soap!

Looking around at my laundry pile, the realization of my maturing young man seeped into my soul. Calvin’s fearlessness in asking me and his innocence spurred me on; my boy trusted me. I should be grateful that Calvin wasn’t asking his buddies and he wasn’t learning this from the “street.” He deserved the honest truth, and Calvin trusted me to give him an answer.

Mustering courage and summoning my first-grade teaching background, I peered into the pile of freshly laundered towels on my bed, and grabbed the first washcloth I saw.

“Calvin, let’s pretend that this washcloth is part of a woman’s body; we’ll call it the uterus.”

I held the washcloth over my face as a shield against the look of terror I knew was slowly growing over Calvin’s expression.

With one eye, I spied a tube sock worthy of a fallopian tube. I fashioned my makeshift female anatomy across my shoulder, using my left hand to keep things in place and my right hand as a fist.

“OK, so the washcloth is the uterus, the sock is the fallopian tube and my hand is the woman’s ovary.” I waved at Calvin with my “ovary” to make sure he understood what I was attempting to explain. Calvin stood in a state of silent shock — his only

protection from my laundry catastrophe. And just as I was looking for another “fallopian tube sock,” Mark knocked on the door and asked, “Can I come in?”

“That’d be great, hon!” I muffled desperately from behind my cotton curtain.

“Why does she have laundry on her face?” Mark asked Calvin.

“I have no clue,” Calvin answered in stoic awe.

I waved my right hand (er, ovary) at Mark and said, “I’m trying to explain the sixth-grade video to Calvin, that’s all.”

“Calvin?”

“Yes, Dad?”

“Go get my laptop. I’ve got some explaining to do.”

Mark and Calvin had the talk while I went back to my laundry duties. And after they were done, Calvin came into the room, gave me a hug and thanked me for trying. I was really quite OK with how things worked out, and Calvin seemed satisfied and untraumatized from my object lesson. I also came to the realization that PIDD kids may know about their bodies, but it’s our responsibility as their parents to be as honest and upfront with them as possible.

And per Mark’s request, we’ve switched from using washcloths to “poufs.” It makes washing our faces a little easier now. ■



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

Questioning My Pride

By Ever Fecske

WHEN LIVING WITH a chronic illness, is there any room for pride? How can people maintain their dignity when disease causes them to lose control over their bodies? My pride flew out the window a long time ago — sometime between the lack of bowel control and the foolish things that come out of my mouth while under an anesthetic.

I bring this issue up because I desperately wanted to share good news. In a previous article, I talked about weaning myself off of prednisone. I was so excited at the possibility that I might be a size-8 bride with only one chin. I began making plans and imagining the next seven months free of any worry about weight, muscle pain or mood swings. I was going to feel beautiful! Because isn't that how a bride should feel? But now I'm thinking that maybe I put too much emphasis on how I wanted everything to be. Or, maybe I'm now trying to de-emphasize what I want because it may not turn out that way.

After being off prednisone for three weeks, my health dramatically declined. My lung capacity dropped from 78 percent to 49 percent. I was inactive because I couldn't breathe. I wanted to sleep all day because I felt terrible most of the time. In my head, I just thought that I was having withdrawals and eventually they would pass, but things got worse. In one week, I had a CT scan, as well as appointments with my immunologist and pulmonologist.



As I could have predicted, my CT was much worse and, as a result, my pulmonologist decided to perform my fourth bronchoscopy. Needless to say — prednisone returned!

It's not odd that I feel discouraged. But, is it odd that I also feel embarrassed? After all, I had it all planned! I told my family and friends that I was off the steroids and doing well, and I was planning to be on the road to recovery. Planning — ha! I guess I should have known better.

So, now, it's all come down to hurt pride — that debilitating and disheartening sense of self. The question is, "What is pride and why is it important?" Is it pride to feel

equal and better, or is it pride to accomplish something? Is pride important, or is survival and happiness more important? I've decided that pride is not to be found in what a person can't control, but rather in the way they handle it. I'm still learning about this. For myself, I know that I can take pride in the manner in which I live and love and treat others. It's all in what I can give back and the kind of person I am. What I do and how I can make the best of a bad situation is where I'll find pride in myself.

So, yes, there is room for pride. In fact, I'm rethinking the self-pity approach, which is something all of us living with an illness can do. We can be proud because we are good people. We do not have to let tough times beat us or even stop us for a minute!

I am re-evaluating my situation and thinking about what I should really take pride in. I am a creative person, I have found someone that I can love forever, I have a chronic illness and yet I cannot be stopped. I have experienced things only a handful of people have experienced, and I am alive. And I am proud! ■



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

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

Caring for the Caregiver

The well-being of caregivers is often overlooked, but their lives can be improved with a strong support group and a lot of laughter.

By Mark T. Haggard



It's 2 o'clock on a late December morning and I'm watching the television in an emergency room. In the bed in front of me, my wife rests comfortably for the first time in a week of her renewed struggles with ankylosing spondylitis. But, I am still gut-wrenched: "Will my wife will be all right?" I asked myself. "When will the next episode requiring a trip to the ER occur?" "How much will this

visit cost?" "Will I need to take time off from work next week?" "How many sick days do I have left?" "How will I finish my Christmas shopping?"

Every time I take one of my family members to the doctor, these same kinds of questions run through my mind. Individuals who live with chronic illnesses understand the financial, emotional and psychological impact of immune difficulties. But,

what's often not understood is the impact these illnesses have on caretakers.

Caregiving and the Immune System

According to research conducted by Dr. Ronald Glaser, professor of molecular virology, immunology and medical genetics at the Ohio State University Medical School, and Janice Kiecolt-Glaser, professor of psychology and psychiatry, caregiving actually has a negative impact on the immune system.

The Glasers' research team noted changes that amounted to a shortened life span of four to eight years due to changes in the caregiver's body at the molecular level. Telomeres are genetic material protecting the end of each chromosome, like the cap on the end of a rope. As cells divide, an enzyme (called telomerase) works to repair the damage to those chromosomes. "Think of it as a frayed rope," the Glasers say. "If the caps weren't there, the rope would unravel." As we age, the telomeres shorten and the activity of the telomerase enzyme lessens. Caregivers of the chronically ill, according to the study results, have a pronounced decrease in telomeres and the production of telomerase.

Further tests conducted during the

study compared a control group of non-caregivers to caregivers, which showed levels of stress in caregivers to be twice that of the control group. Caregivers also had fewer lymphocytes, an important component of the immune system, and higher levels of cytokines.

Life as a Caregiver

Eighteen-year-old Cathryn Achilles of Wheatland, Calif., recently graduated from high school; she had been home-schooled by her mother, Deanna. Cathryn lives with ataxia telangiectasia (AT) and Deanna says that, because AT compromises the patient's muscle control, taking care of her is a 24-hour-a-day job. "Every time I think I can leave, I end up regretting it," Deanna states. At times, while her daughter was sleeping, Deanna would leave for only a few minutes and return to find that Cathryn had fallen and injured herself.

Caregiving actually has a negative impact on the immune system.

It's also tough on Cathryn's siblings. "The older they get, the more I find out how hard it's been," Deanna says. Older sister Crystal, a fiery independent type who shared a room with Cathryn, complains that "Cathryn gets catered to." While growing up, younger brother Robert had to give



up much of the limelight to his sister.

Deanna says that she is in complete control of the care-giving situation, and it is only when something out of the ordinary occurs that she feels out of sorts. During a recent trip to a Bay Area hospital, Deanna broke down from the stress. After first refusing to admit her daughter, the doctors demanded X-rays that would have contributed to the deterioration of Cathryn's already compromised body. Because of continual miscommunications with the doctors at the hospital, she put herself on a "24-hour watch" at Cathryn's bedside. Deanna "lost it" on the third day when a nurse started an IV medication in Cathryn's line that was prescribed for the child in the next bed.

Coping as a Caregiver

Maya Hennessey is a "family caregiver specialist" in Chicago, and author of *If Only I'd Had This Caregiving Book*. She is the Midwest coordinator for the National Family Caregivers

Association, an organization that is committed to providing services to caregivers at no cost. Hennessey has devoted the last 30 years to collaborating with treatment providers to improve caregiving for families. She has found that caregiving creates demands — physically, emotionally and spiritually. Normally, the body has a chance to recover from those demands once an episode has passed, but when these demands are constant, as in the case of a long-term illness, the body does not have the opportunity to recover, and the immune system is weakened.

For help, Hennessey recommends a strong network of support, looking within your own group of friends and neighbors. "You have to look within your own circle and see who is available and willing to help," she explains. "Sometimes it won't be immediate family." Deanna has found support in the emails and Facebook pages of her cyberfriends who have family members with AT. "No one else can understand

the uniqueness," Hennessey adds.

When asked how we are doing, we caregivers often answer, "Fine." Perhaps that is for the protection of those whom we run into. One day while shopping, Hennessey ran into a friend who asked how things were going, and she responded with a 30-minute explanation. A few days later, the two spied each other on opposite sides of the store; Hennessey started walking toward him and he turned heel and ran to the exit. Talking to another friend the next day, Hennessey thought that he might still be running!

Rather than give the standard answer of "fine," Hennessey advises

we delegate, the pressure does mount on caregivers and we begin to burn out. Hennessey says that we need to find things in our own lives — maybe things we've given up on — that have always been healing and comforting. Deanna admits: "I check out a lot. I look at my friends' Facebook pages. I like to read the classics; they are a great escape." She also says that her faith keeps her grounded: "I'm most stressed when I'm out of my [Christian] walk."

For Hennessey, "Going out with my girlfriends and laughing was important, but when my husband got sick, life was not so funny. I was out at a function and a friend intro-

were punctuated by bouts of uproarious laughter. Dr. Bill Cosby once noted, "If you can laugh at it, you can get through it."

I subscribe to the adage: "Those who refresh others will be refreshed themselves." Refreshing others has helped me cope with my own family's immune issues; it is an opportunity for me to help people laugh, relating the humorous side of what our kids do despite their afflictions. We need to laugh. We need to make others in our situation laugh. We have to be the support system that someone else somewhere needs. We need to give life back to those who are having life stolen from them.

That night in late December, in the midst of my long list of life questions, my wife turned toward me and produced a Dilaudid-induced smile. The turn put my mind at ease and I leaned closer to her, returned her smile and asked, "Can I have some?" I could almost feel my financial, emotional and psychological worries being washed away in a rush of serotonin. That night, a few more months were added to my life. ■

Rather than give the standard answer of "fine," Hennessey advises caregivers to have a short list of things that others could do to help take the pressure off them.

caregivers to have a short list of things that others could do to help take the pressure off them. People are not going to know what you need if you don't tell them. And, if you ask, you will find that people are willing to help with errands, mowing the lawn, making phone calls or preparing a meal. "You have to begin constructing your life around delegating and asking for help," Hennessey says.

Nevertheless, no matter how much

duced me to two other caregivers and we started sharing experiences and laughing and finding humor in our situations. That night, I slept like a baby."

Laughter Is Medicine

Laughter is great medicine. Laughing releases endorphins that make us feel better and also increases levels of serotonin, a hormone that counters depression. My interviews with Hennessey and Deanna for this article

Sources

National Family Caregivers Association:
www.thefamilycaregiver.org, (800) 896-3650
 If Only I'd Had This Caregiving Book:
www.mayahennessey.com/maya_book.php,
 (800) 280-7715



MARK T. 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.

Treating Asthma

By Kris McFalls



ASTHMA IS ONE of the fastest growing disease states, affecting 17 million Americans. The lung disorder often occurs in patients with a history of chronic infection, brought on by chronic inflammation and/or narrowing of the airways. But, with proactive, consistent care and treatment, patients can control their asthma and lead a very active life.

Tracking the Numbers

Patients who regularly monitor their peak flow numbers have a better chance of keeping their asthma under control and often can spot trouble before it becomes a crisis. They can do this using a peak flow meter, which is a simple device designed to help patients with asthma monitor and track variations in breathing.

Peak flow meters come in two forms: analog and digital. An analog monitor has no bells or whistles, is simple to use and maintain, and levels are recorded manually by the patient. A digital peak flow meter tends to be more accurate and has the capability to record data automatically. Because of its extra features, however, a digital meter costs more than an analog meter.

Less Room for Error

Managing asthma requires the use of inhalers or nebulizers.

Inhalers. Inhalers offer quick, convenient treatment. However, studies show that the majority of patients fail

to use proper techniques when utilizing an inhaler. Many patients struggle with the coordination and timing needed to ensure that the full dose of medication ends up in the lungs instead of in the air. Utilizing a spacer device with a metered inhaler can help maximize the medication dispensed. A spacer, which can be fitted with either a mouthpiece or face mask, is a large air chamber fitted to the opening of the inhaler that slows down the dispensation speed of the medication. Using a spacer with corticosteroid also can help reduce some of the side effects caused by medication residue in the mouth.

Nebulizers. Nebulizers operate by mechanically transforming liquid medication into a fine mist for inhalation. In fact, some adult patients prefer the fine, moist mist associated with a nebulizer instead of an inhaler. In addition, a nebulizer may be best for young children, in particular, because it is the best way to ensure proper dosing.

There are three kinds of nebulizers: jet, mesh and ultrasonic. The most commonly used is the jet nebulizer, which is connected to a compressed air source with tubing. The other end of the tubing is connected to a mouth piece or face mask for inhalation. Jet nebulizers are relatively inexpensive and may be covered by insurance under the durable medical equipment benefit.

Mesh and ultrasonic nebulizers have come about mostly due to patients' desires to lead a more active lifestyle away from home. These devices use high-frequency vibrations to turn medication into mist, and generally, they are battery-operated, hand-held and free of tubes and cords. And, while treatment time is usually shorter than the traditional jet nebulizers, costs are higher and may not be covered by insurance.

Living with Asthma

Asthma is a condition that cannot be cured, but with good communication, consistent record keeping and today's technologies, it can be managed effectively, and patients can expect to lead a full and active life. ■

KRIS MCFALLS is the full-time patient advocate for IG Living magazine.

Directory of Inhalers, Flow Meters and Nebulizers



AeroChamber

AeroChamber Plus is designed to maximize the delivery of metered-dose inhaler medications to patients' lungs and decrease deposition of medication in the mouth

and throat. AeroChamber eliminates the need to coordinate activating the MDI with inhaling the medication. It is available in three mask sizes and without a mask.

www.aerochambervhc.com/patient/default.aspx

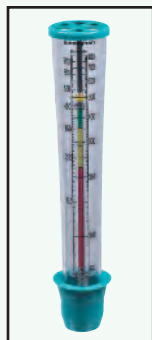


Mabis Healthcare

The CompMist Compressor Nebulizer is a self-contained unit that is designed to be an affordable alternative to bulky compressors of the past. Several key features make it a highly functional system

in home respiratory care, including a convenient and easy-to-carry handle, two compartments for storing tubing, accessories and a power cord, and a built-in nebulizer holder for hands-free medication delivery.

shop.mabisdmi.com/e2wltemMain.aspx?parentID=IT00000371&parentLink=2100000107:3100000433;
(800) 526-4753



Monaghan Medical Corporation

The one-size-fits-all TruZone PFM uses a logarithmic scale, which makes it easy for patients of all ages to determine significant changes in their peak expiratory flow and to record their peak flow readings. ColorZone tapes eliminate the need for mathematical calculations when determining zones and are easy to apply. TruZone PFM is easy to hold in any size

of hand, and is convenient and portable.

www.monaghanmed.com/products/consumer/truzone-peak-flow-meter-pfm; (519) 455-7060



nSpire

PiKo® monitors measure peak flow, FEV1, FEV6 and FEV1/FEV6 to provide a solution for asthma and COPD management. Sophisticated features include automatic test quality alerts and elec-

tronic data storage of 96 tests. Data can be reviewed via a single operating button, and all tests can be easily downloaded to the companion PiKoNET software.

www.nspirehealth.com/default.asp?LINKNAME=PIKO-6_MONITOR; (800) 574-7374

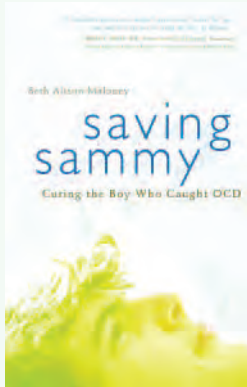
Omron



The Portable Nebulizer with VMT NE-U22V utilizes Vibrating Mesh Technology (VMT) to efficiently deliver solution medications for patients suffering from asthma, COPD or other respiratory conditions. Its small size and carrying case make it easily transported. The nebulizer provides powerful delivery comparable to table-top compressor nebulizer systems to bring effective relief and control of the disease.

www.omronhealthcare.com/product/1137-201-respiratory-devices-portable-nebulizer-with-v.m.t.-ne-u22v; (877) 216-1333

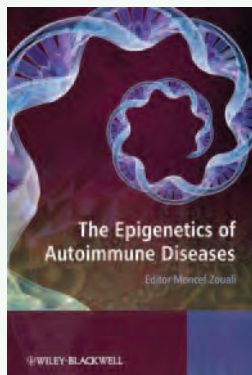
Book Corner



Saving Sammy *Curing the Boy Who Caught OCD*

Author: Beth Alison Maloney
Publisher: Crown Publishing Group, a division of Random House,
www.randomhouse.com/crown

Driven by her desire to help others, Beth Maloney describes her journey to find what is wrong with her son with heart and passion. The book describes how the author's son, Sammy, a bright and charming boy, suddenly began to exhibit disturbing behavior. He walked and ate with his eyes shut, refused to bathe, burst into fits of rage, slithered against walls and used his limbs instead of his hands to touch light switches, doorknobs and faucets. Part manifesto, part medical mystery, *Saving Sammy* is an empowering and inspiring story of a mother's determination to save her son, take on the medical establishment and win.

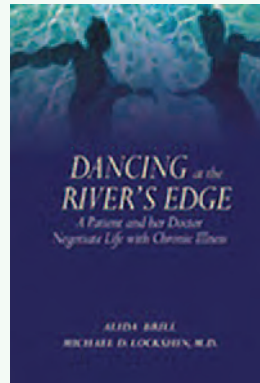


The Epigenetics of Autoimmune Diseases

Editor: Moncef Zouali
Publisher: Wiley,
www.wiley.com

This book covers the latest discoveries and developments in epigenetics and their significance in a variety of autoimmune diseases, including rheumatoid arthritis, autoimmune anemia, type 1 diabetes, multiple sclerosis,

autoimmune gastritis, thyroiditis and system lupus erythematosus. Chapters are written by world-class experts in their respective fields and are divided into four parts: transcription factors (partners of immune tolerance to self); epigenetic modifiers of autoimmunity; influence of environmental factors on epigenetics of autoimmunity; and stress responses that break immune silence.



Dancing at the River's Edge *A Patient and Her Doctor Negotiate a Life with Chronic Illness*

Author: Alida Brill
Publisher: Schaffner Press,
www.schaffnerpress.com

This dual memoir by Michael Lockshin, a rheumatologist, and his longtime patient Alida Brill, who is suffering with a chronic illness (an atypical form of Wegener's granulomatosis developed at a young age) explores their unique relationship and bond based on trust, respect and honesty formed over two decades. Chapters in the book alternate between Brill's writings and Lockshin's writings to bring perspective to the patient/doctor dialogue. They discuss the constant day-to-day frustrations and ongoing crises suffered by a patient who is chronically ill, as well as the mental struggles and conflicts the concerned doctor must face in deciding what's best for a patient without compromising the patient's personal freedoms.

This intimate portrait of the delicate balance between doctor and patient is intended to help people who struggle with chronic illness, and the friends and family who support them. All topics are discussed, ranging from sex and suicide, to careers, fears and loneliness. ■

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

IG Manufacturer Websites

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

Disease-State Resources

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
- The Neuropathy Association: www.neuropathy.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
- The Neuropathy Association: www.neuropathy.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_Whatsl.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.umdff.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



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. (703) 299-4850

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



The Cure JM Foundation www.curejm.com (760) 487-1079

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.myositissupportgroup.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



The Neuropathy Association, www.neuropathy.org, is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association's mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, advocate the need for early intervention and support research into the causes and treatment of neuropathies. (212) 692-0662


- Neuropathy Action Foundation: www.neuropathyaction.org

Online Peer Support

- Calgary Neuropathy Support Group: www.calgarypnrs.org

Primary Immune Deficiency Disease (PID)

Websites



The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. (800) 296-4433

Jeffrey Modell JM Foundation

The Jeffrey Modell Foundation, www.info4pi.org, is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency. (212) 819-0200

- The National Institute of Child Health and Human Development (NICHD), www.nichd.nih.gov, is part of the National Institutes of Health. Go to the "Health Information and Media" tab on the website and do a search under
- 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

- IDF Common Ground: www.idfcommonground.org
- IDF Discussion Forum: my.primaryimmune.org/forum
- IDF Friends: www.idffriends.org
- Jeffrey Modell Foundation Message Board: www.info4pi.org
- Rhode Island peer group: <http://health.groups.yahoo.com/group/RhodelslandPIDD>

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

Other Resources

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

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.

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Temecula, CA 92591-9815

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