

How to Cope

Getting the Support You Need

Preparing for IG Copays & Deductibles

Exercise: What and How Much?

Chronic Conditions
and Self-Image

Medical Information
in a Flash

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About *IG Living*

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

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Exercise: A Can-Do Attitude



FOR MANY IN the *IG Living* community, exercising may seem like an impossibility. Managing to get out of bed and function each day may seem all that is possible. But research shows that exercise can improve joint function and energy levels, as well as immune response, in individuals who suffer from immune disorders. Knowing this, the question, then, is really not a matter of “Can I?” but “Will I?”

According to Tammy Thomas, a registered dietitian, certified and degreed strength and conditioning specialist, and trainer and consultant for individuals with rheumatoid arthritis and other autoimmune diseases, people who suffer from immune disease who want to exercise fall into two groups: the “can and do” group and the “can’t but want to” group. Tammy herself went from the latter to the former group after being diagnosed with severe, erosive rheumatoid arthritis (RA). Today, she regularly performs cardiovascular and strength exercises, making her a prime example of how exercise can help with an autoimmune disease. But, she emphasizes that the difference between her and “healthy” individuals is that she exercises at a much more compromised capacity.

While her doctors have expressed concern about overaggravating and exacerbating the inflammatory process of RA with weight training (a concern she calls outdated), current medical literature on RA and strength training has shown improvements in function, strength, range of motion and disease activity scores. And, she says that cardio training is important for keeping off extra weight that can burden compromised joints, as well as for increasing aerobic capacity — especially for individuals whose chronic condition includes diminished aerobic capacity and/or increased risk for cardiovascular diseases.

As Tammy explains, “Exercise is something the body was designed to do. It has an amazing capacity to withstand intense heavy lifting and aerobic work, resulting in very positive and beneficial physiological adaptations that increase the body’s efficiency on several functional levels.” But exercise doesn’t have to be intense to produce results. She suggests focusing on exercise frequency rather than intensity.

Researchers also believe that exercise may help those who suffer from immune disorders. In January, a new study was begun to study the benefits of exercise on autoimmune disease. A collaborative effort between the Diabetes Research Institute and the Università degli Studi di Milano in Milan, Italy, this study is based on a hypothesis developed by two researchers that physical exercise exerts a potent immunomodulatory effect, reducing the autoimmune response that in type 1 diabetes attacks and destroys the insulin-producing cells. According to the researchers, positive results will have implications for many other autoimmune diseases beyond diabetes, such as psoriasis, lupus and RA.

There’s never a better time than the present to start on a program of regular exercise. In this issue, Matthew Davis Hansen, a practicing physical therapist, provides an outline for how to motivate yourself to exercise and how to choose a suitable exercise program and stay injury-free. If you or someone you care for has been struggling with the question of “Can I?” or “Will I?” his article, Exercise and Immune Disease, provides the groundwork for a perfect starting place, or in some people’s cases, the perfect picking-up place. ■

Ronale Tucker Rhodes, MS, Editor

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

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MATTHEW DAVIS HANSEN,
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*Physical Therapist and President,
Allied Healthcare*

Exercise and Immune Disease

“Regardless of a patient’s current situation, there is almost assuredly an exercise program that will improve their physical, emotional and/or mental well-being.”



ERIKA LAWRENCE
*Associate Professor of
Clinical Psychology, University of Iowa*

How to Cope

“Being good at providing support and help is a skill that needs to be learned.”



LAUREN GERSTMANN, MPH
*Genetic Epidemiology Program,
University of Southern California
Department of Preventive Medicine*

Chronic Conditions and Self-Image

“The medical community is slowly starting to realize that the emotional effects and frustrations of chronic illness impact patients’ health.”



KRIS MCFALLS
Patient Advocate, IG Living magazine



TERRY STONE
Territory Manager, NuFACTOR

IG Copays and Deductibles on the Rise

“The waiving of copayments and deductibles based on financial need is known as charity care, financial assistance or compassionate care.”

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



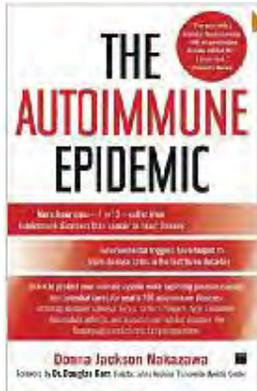
IGL’s Readers Group Teleforums allow readers to connect with others to share their experiences living with chronic diseases. Here’s how you can participate:

- 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.

Book Corner



The Autoimmune Epidemic

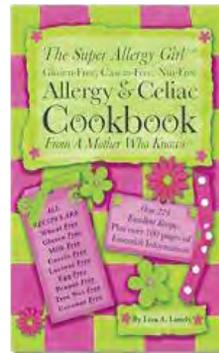
Bodies Gone Haywire in a World out of Balance and the Cutting Edge Science that Promises Hope

Author: Donna Jackson Nakazawa
 Publisher: Touchstone/Simon and Schuster,
www.simonandschuster.com

In *The Autoimmune Epidemic*, author Donna Jackson Nakazawa explains the disturbing ways that “auto-gens” — a term she coins to denote chemical, lifestyle and other triggers of autoimmune disease — are wreaking havoc with the human immune system. Nakazawa offers a course for hope, detailing the personal, political and economic choices that can help curb this epidemic.

The book combines research from today’s cutting-edge scientific labs with the frontline perspective of autoimmune sufferers. Topics explored include:

- what role chemicals, heavy metals, viruses, diet, stress, lifestyle and genes play in developing autoimmune disease
- how modern lifestyles and environmental contamination have created a “perfect storm”
- the connection between autoimmune disease and allergies
- the fact that 75 percent of autoimmune sufferers are women
- the connection between autoimmune disease and fibromyalgia and chronic fatigue
- the fact that the average American woman is eight times more likely to have autoimmune disease than breast cancer
- ways in which readers can lessen the multitude of exposures that threaten their immune systems
- groundbreaking interventions from today’s top labs — from Harvard to Hopkins — that promise to help halt the disease process.



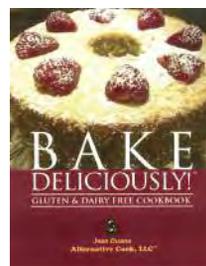
The Super Allergy Girl Allergy & Celiac Cookbook

From a Mother Who Knows

Author: Lisa Lundy
 Publisher: The Rooster Crows,
www.theroostercrows.com

As a lifelong food allergy sufferer and the parent of three food-allergic children, author Lisa Lundy writes from experience in her cookbook dedicated to improving the lives of the more than 75 million Americans suffering from various food intolerances and sensitivities, the 2.2 million American celiac (gluten) disease sufferers and 12 million Americans faced with life-threatening food allergies.

More than a cookbook, this publication is a textbook on the study of cooking for (and living with) food allergies, celiac disease and intolerances. It offers cooking tips and a survival guide to what should and should not be eaten, as well as resources, products, recipes and information that will help consumers, practitioners and organizations. Overall, there are 225 recipes and more than 100 pages of information.



Bake Deliciously! Gluten & Dairy Free Cookbook

Author: Jean Duane
 Publisher: Alternative Cook, LLC,
www.alternativecook.com *Bake*

Deliciously! features more than 150 baked items without gluten, dairy (CFCF) and other common allergens, and provides options for those suffering from celiac disease, gluten or dairy intolerance, food allergies and other diseases. The author provides readers with a thorough understanding of substitutions and realistic expectations, and most recipes can be completed in five steps or less.

Insurance

Therapy Prices Rising Under Tier IV Categories

Patients who need chronic lifesaving therapies, such as biological response modifiers, clotting factor, chemotherapy, monoclonal therapy, intravenous immune globulin therapy, etc., may now have to pay for them under Tier



IV and Tier V categories in private healthcare plans, as well as Medicare Part D plans, TriCare and the Federal Employees Health Benefit Program. Previously, chronic lifesaving therapies were covered under a health insurance company's major medical plan. But in recent years, these therapies were switched to be covered only under Tier I, II and III categories; the higher the tier number, the higher the copay. Under Tiers IV and V, patients will be required to pay a 10 percent to 30 percent copay for their therapy, which means more patients will be unable to afford their lifesaving therapies.

Healthcare professionals should advise their patients to look at their choices in health insurance plans and to review the entire list of drugs/therapies to see where each one is covered. If therapies fall under Tier IV or Tier V, other options should be considered. ■

Healthcare

Pneumonia Vaccine Can Limit Swine Flu Deaths

To reduce hospitalizations and deaths associated with the H1N1 (swine) flu, public health authorities are recommending that individuals get inoculated with the pneumonia vaccine. Pneumovax, manufactured by Merck & Co., stimulates the body's ability to neutralize the bacteria responsible for many cases of pneumonia and protects against infection from *Streptococcus pneumoniae* (*S. pneumoniae*). Preliminary results presented to the Centers for Disease Control and Prevention vaccine committee in June indicated that about 40 percent of swine-flu-related pneumonia had an unknown cause, and about 30 percent were caused by *S. pneumoniae*. This suggests that at least one-third of

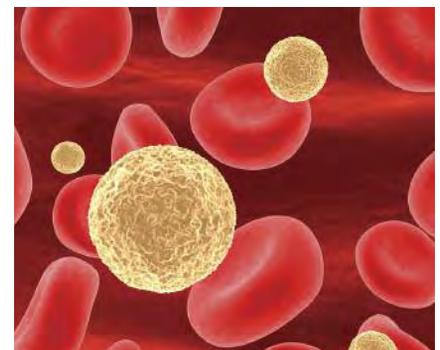
flu-related pneumonia deaths could be prevented by vaccination. Further, the vaccine provides protection against pneumonia for up to 10 years, meaning one vaccination provides at least some safeguard not just this year, but for future flu seasons as well.

Unfortunately, the recommendation has gone largely unnoticed, according to Dr. William Schaffner, chairman of the preventive medicine department at Vanderbilt University School of Medicine and president-elect of the National Foundation for Infectious Diseases. Sales of Pneumovax have not increased in the U.S. since June; however, they have risen in Europe in response to similar recommendations by health authorities there. ■

Research

T Cells Influence Aggressive Cells

University of Michigan scientists have discovered that the immune system's regulatory T cells influence aggressive immune cells, a discovery that might offer new avenues of therapy for conditions ranging from autoimmune diseases to organ transplants and cancer. Study results, published online ahead of print in *Nature Chemical Biology*, found that regulatory T cells appear to alter the chemical environment around their aggressive cousins, known as autoreactive T cells, in ways that either suppress them or cause them to proliferate. Autoreactive T cells are thought to cause multiple sclerosis, Crohn's disease,



rheumatoid arthritis, lupus and a host of other autoimmune diseases. To protect against these diseases, researchers want T regulatory cells to restrain excessive action by autoreactive T cells. But to control cancer, researchers want to partially inhibit T regulatory cells so that autoreactive T cells will be able to identify and vigorously attack cancer cells. ■

Research**New Drug Approved for Chronic ITP**

Patients suffering from chronic immune (idiopathic) thrombocytopenic purpura (ITP), an autoimmune disease

that dramatically reduces the number of platelets in their blood, causing bruises, nosebleeds and, rarely, life-threatening brain hemorrhages, may now benefit from a new drug that is found to effectively raise platelet counts and lower bleeding. This is especially promising for patients who have had an insufficient response to corticosteroids, immunoglobulins or splenectomy.

The drug, Promacta, was recently granted accelerated approval by the FDA in response to phase III clinical trial results. In the phase III study reported on in *The Lancet*, 114 sub-

jects, all 18 years and older with at least six months of history with ITP and low-platelet counts of 30,000 per microliter of blood, were split into two groups: Two-thirds were in the experimental group that received the standard of care with the addition of 50mg of eltrombopag (Promacta), and the other third received the standard of care and a placebo pill. Fifty-nine percent of subjects receiving Promacta achieved platelet counts at or over 50,000 per microliter of blood, compared with 16 percent of subjects in the placebo group. ■

Research**Th-17 Cells Culprit of Autoimmune Disease**

Recent research points to overactivity of Th-17 as the culprit behind autoimmune disease, a condition that causes the body to attack its healthy cells, resulting in disorders such as rheumatoid arthritis, psoriasis and graft-versus-host disease (GVHD). According to a study published in the February issue of *Blood*, researchers injected bone marrow into mice with normal Th-17 levels. When they then gave the animals additional Th-17, the mice developed GVHD. Although GVHD is not a true autoimmune disease, it

involves an overactive immune system incorrectly attacking tissue and has many of the same symptoms as autoimmune diseases. “[Th-17 cells] appear to be able to cause a significant amount of GVHD symptoms,” says Jonathan Serody, co-author of the study and a hematologist and researcher at the University of North Carolina School of Medicine in Chapel Hill. “Our hope would be that you could come up with therapies specific to these cells.”

To decrease levels of Th-17 in the body, scientists in the molecular immunology laboratory at New York University are hoping to deactivate the protein that tells the system to boost Th-17 production. That protein hibernates until a specific molecule slips into its tiny pocket like a key in a lock. Fabio Santori, a researcher at NYU who is trying to identify the shape of the keyhole,



says that targeting Th-17 could hold potential for pharmaceutical therapies of autoimmune diseases. Other scientists are taking a different approach to combating Th-17 by silencing the molecules that help cells communicate with each other. By blocking communication between the cells, they believe they will be able to tame the body’s production of Th-17 and halt destruction of the body’s healthy cells. ■

Did You Know?

A new book titled *The Autoimmune Epidemic* has recently been released. Read more about the book on page 7.

Insurance

Uninsured Workers Rate Climbs

A significantly higher number of workers are uninsured now than compared to a decade ago. According to a study conducted at the State Health Access Data Assistance Center at the University of



Minnesota, “During the mid-2000s, 26.9 million U.S. workers were uninsured, about 6 million more than the 20.7 million uninsured workers in the mid-1990s.” In addition, 20 percent or more of the working-age population is uninsured in 14 states, compared to only eight states in the 1990s.

The researchers attributed the growth in uninsured workers to costs, since total premiums for employer-sponsored plans have increased six to eight times faster than wages. “The thing I think is interesting is how many workers are newly uninsured,” said Lynn Blewett, the study’s lead researcher and director of the Center. “In the last couple of years, we’ve seen a deterioration of private health insurance.”

The study was reported on in the March 24, 2009, edition of the *Kaiser Daily Health Policy Report*. ■

Research

Tobacco May Prevent Autoimmune Diseases

In the future, the ingestion of tobacco may help to assist in the treatment of several autoimmune and inflammatory diseases, including diabetes. Scientists have genetically altered tobacco plants to produce biologically active interleukin-10 (IL-10), a potent anti-inflammatory cytokine (a category of signaling molecules that, like hormones and neurotransmitters, are used extensively in cellular communication). Two versions of IL-10 (one from a virus and one from a mouse) were used to generate plants in which this protein

was targeted to three compartments within the cell.

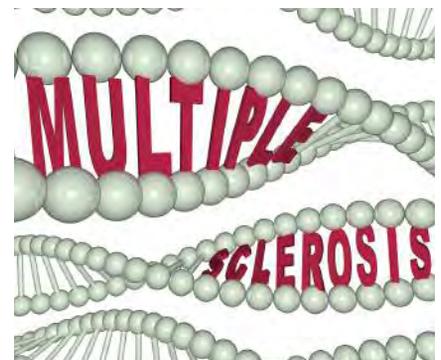
According to the article published about the study in the open access journal *BMC Biotechnology*, the researchers found that tobacco plants were able to process both forms of IL-10 correctly, producing the active cytokine at high enough levels. This means that it might be possible to produce medicines without a lengthy extraction and purification process. The next step is to feed the plants to mice with autoimmune diseases to see how effective they are. ■

Research

MS Reversed with Treatment

A new experimental treatment for multiple sclerosis, an autoimmune disease in which the body’s own immune response attacks the central nervous system, completely reverses the disease in mice, and researchers predict it might work the same way in humans. The new treatment, named GIFT15, was discovered and tested by a team led by Dr. Jacques Galipeau of the Jewish General Hospital Lady Davis Institute for Medical Research and McGill University in Montreal, Quebec.

GIFT15 is composed of two proteins — GSM-CSF and interleukin-15 — fused together artificially in the lab. Normally, the proteins act to stimulate the immune system, but in their fused form, the equation reverses itself. This effect, explains Galipeau, converts B cells — a common form of white blood cells normally involved in immune response — into powerful immune-suppressive cells. However, Galipeau cautions that multiple sclerosis must be caught in its earliest stages, and clinical studies are needed to test the treatment’s efficacy and safety in humans. No significant side effects showed up in the mice, and the treatment was fully effective with a single dose. ■



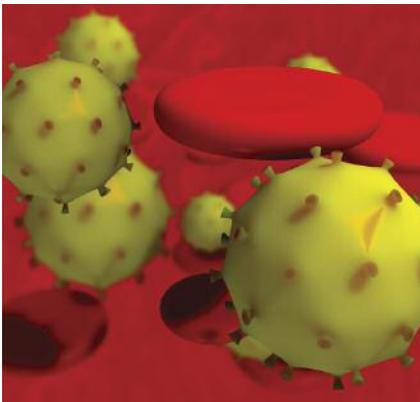
Research**RA Drugs Raise Shingles Risk**

In a recent study, individuals taking Remicade or Humira for rheumatoid arthritis had almost double the risk of developing shingles.

Conducted by researchers at the German Rheumatism Research Centre in Berlin, the study looked at 5,040 people taking the TNF blockers infliximab (Remicade) or adalimumab (Humira), the fusion protein etanercept (Enbrel) or the monotherapeutic drug anakinra (Kineret). Participants presented with 86 cases of shingles, 39 of which were deemed related to treatment with one of the two TNF

blockers, and 24 of which were attributed to treatment with conventional medications. In addition, the cases of shingles observed in the study were worse than those usually seen in the general population, with 20 percent of the cases categorized as "severe" and 13 percent requiring hospitalization.

A vaccine against shingles is available and recommended for people age 60 and older, but it has not been studied in those with rheumatoid arthritis or people taking TNF blockers. ■

Vaccines**SCID Patient Develops Rotavirus**

The first reported case of persistent shedding of the rotavirus vaccine in a patient with severe combined immune deficiency (SCID) is examined in an article in the August 2009 issue of the *Journal of Allergy and Clinical Immunology*. The case involves a 9-month-old infant girl who was examined in the hospital after a history of faltering growth and chronic diarrhea. After receiving immunizations according to recommended schedule, including a

rotavirus vaccine administered at 2, 4 and 6 months, the patient developed persistent diarrhea and vomiting with poor weight gain that became worse at 6 months. Stool sample tests showed the presence of the rotavirus strain that matched that of the vaccine she had received. The patient was diagnosed with SCID and given a successful transplantation of cord blood at age 11 months and two-and-a-half months later, which resulted in no further traces of rotavirus in her stool.

Vaccines can present problems for immunosuppressed patients, and some vaccines are not recommended for these individuals. Since primary immunodeficiencies, such as SCID, are usually diagnosed within the first year of life, the article's authors concluded that it is important that healthcare providers consider this diagnosis when managing patients with faltering growth and chronic diarrhea. ■

Research**Tracking Autoimmunity Development May Stop It**

New research sheds light on a way to track the development of autoimmune diseases before the onset of symptoms. Researchers at the University of Oslo engineered the NF- κ B molecule (which is activated by inflammation and which plays a key role in autoimmune disease development) to emit light when activated. Using a mouse model of systemic autoimmunity with features of lupus, the researchers found that NF- κ B activation signals were present in affected organs several weeks before the clinical manifestations of the disease. And, the light signal intensity correlated with disease progression.

Since early detection of autoimmune disease is critical for assessing new treatments, tracking NF- κ B may provide a new tool in the evaluation of early autoimmune therapies. Future studies will utilize this new model for studies on early intervention, such as drug treatment, to prevent or treat autoimmune disease. ■

Did You Know?

Blood sugar testing strips should not be used by patients who are taking IG containing certain sugars other than glucose, or who are on dialysis. They can falsely elevate glucose readings and lead to insulin overdose. Six deaths have occurred since last year.

— U.S. Food and Drug Administration

IG Copays and Deductibles on the Rise



By Kris McFalls and Terry Stone

No person or entity is immune to the consequences of increasing healthcare costs. American employers experienced a 119 percent premium increase between 1998 and 2008.¹ To keep employees insured, many employers have been forced to shift some of the costs to employees through higher copays, coinsurance and deductibles, in addition to sharing a higher cost of premiums. For patients requiring immune globulin (IG), the increased burden has forced them to make some very tough decisions that could have lifelong consequences on their health and financial stability. As a result, more and more patients are seeking help to pay for their out-of-pocket IG expenses.

While the monthly cost of IG exceeds the average American monthly income, the profit margins for IG at the provider level are quite small and are shrinking. At times, Medicare reimbursement doesn't cover providers' acquisition and administration costs, which has forced many infusion clinics to close their doors to Medicare patients altogether. Private insurers faced with increasing healthcare costs have followed Medicare's lead by cutting reimbursement rates to providers. The end result is that patients are asked to share more of the financial burden.

A Historical Look at Copayments

Patients often first look to the provider of their IG for some financial relief. Their belief is that because the provider is billing thousands of dollars a month, it can afford not to collect from patients who are adding a great deal of revenue to their bottom line. In fact, in the not-too-distant past, patients frequently demanded providers write off their copayments in return for their business, and providers often agreed. For their part, many providers offered gifts and promised not to charge copayments in an effort to get more business. Taking a historical look at the hemophilia community provides some understanding of practices of the time that caused insurance companies to restructure their reimbursement policies.

Hemophilia is a disorder in which one of the 13 proteins

For patients requiring IG, the increased burden has forced them to make some very tough decisions.

needed to form blood clots is reduced or missing entirely. The clotting process, or clotting cascade, requires all proteins to work together to make a clot. When one of the proteins is deficient, the clotting process stops at that protein, and bleeding continues. There are different severity levels of hemophilia: mild, moderate and severe. People with hemophilia do not bleed faster than others; they simply bleed longer. The treatment for hemophilia is to replace

the missing or deficient protein via clotting factor that is administered through an IV. Prophylactic treatment continues to be the protocol for approximately 60 percent of all hemophilia patients who are classified as severe.



And clotting factor is very expensive. For an adult hemophilia patient, therapy can cost as much as \$350,000 per year, and years ago, profit margins for providers were large. Under those circumstances, many patients felt that providers could afford to give some of that money back to the patients. And, prior to new federal regulations, some hemophilia homecare companies offered patients enticements to stay with their service or come to them for service. Gifts such as pagers for emergency use, large refrigerators for factor storage, and even help with general expenses like rent, were not uncommon. As this kind of assistance continued, over time, patients felt entitled to these extras.

Current Reimbursement Policies and Law

As costs soared and abuse increased, insurance companies took a hard look at the cost of expensive medication such as factor and IG. To rein in costs, insurance companies changed their reimbursement policies, resulting in drastically decreased reimbursement rates for providers. And, as part of the cost-cutting measures, third-party administrators of prescription drug programs, known as pharmacy benefit managers (PBMs), were employed. It is PBMs who negotiate special contract rates with drug manufacturers to help reduce costs for insurers. In addition, some insurance com-

panies opened their own specialty pharmacies to provide medications exclusively to their members, while other insurers restricted provider options to a select few. As a result, specialty pharmacies that continue to provide services to select patient groups, such as the IG and factor communities, are experiencing market compression with reimbursement rates far less than in previous years.

Government, too, soon caught on to the abuse in the system and enacted many laws to stop it. These laws, which are regulated by the Office of the Inspector General (OIG), specifically prohibit giving goods and services to patients and routinely waiving copayments and deductibles. If a gift or service has a value greater than \$10, and if the accumulative yearly value of gifts is greater than \$50, the giver is subject to fines and penalties. However, there is one exception to the latter law that allows companies to forgive copayments or deductibles based on financial need. Specifically, the law states that "non-routine, unadvertised waivers of copayments or deductible amounts [can be] based on individual determinations of financial need or

exhaustion of reasonable collection efforts."²

The waiving of copayments and deductibles based on financial need is known as charity care, financial assistance or compassionate care. Regardless of the name,

While currently there are no programs to specifically help cover out-of-pocket IG expenses, there are programs that may help cover the costs of other prescriptions patients may need.

IG Manufacturer Loyalty Programs

IG manufacturers will provide temporary access to patients' product in the event of loss of insurance. However, patients must first sign up for the manufacturer's service to qualify. These links, phone numbers and email addresses will bring patients directly to where they can sign up.

Baxter Gammagard GARDian:

<http://www.mygardian.com/gardian>

CSL Behring Assurance:

<http://www.csلبهرingassurance.com>

Grifols:

(800) GRIFOLS, option 3

Octapharma:

reimbursement@octapharma.com

Talecris Gamunex Connexions:

<https://www.gamunexconnexions.com>

providers will not advertise that they have this kind of program, because doing so is strictly prohibited by OIG regulations. To inquire about qualifications, patients need to ask to speak with a reimbursement specialist at the facility where they have outstanding debt. They should be ready to give information regarding their income, and if requested, provide proof. While each provider may have different eligibility requirements, patients need not be destitute to qualify for assistance. Also, patients may qualify one year but not the next. Each year, providers review and update their policies, and each year, patients are required to resubmit their applications.

Accessing Financial Assistance

While currently there are no programs to specifically help cover out-of-pocket IG expenses, there are programs that may help cover the costs of other prescriptions patients may need. Organizations such as NeedyMeds will help pay for other medications, freeing up patients' money to help cover the costs of IG. More information can be found at www.needymeds.org.

Primary immune deficient patients with private insurance may qualify for premium assistance through Patient Services Inc. Assistance is limited and based on financial need. Information about premium assistance can be found at www.uneedpsi.org.

If patients lose their insurance coverage, IG manufacturers have loyalty programs that will give them temporary access to their particular product. However, patients must sign up for the service before they need it. See IG Manufacturer Loyalty Programs on page 14.

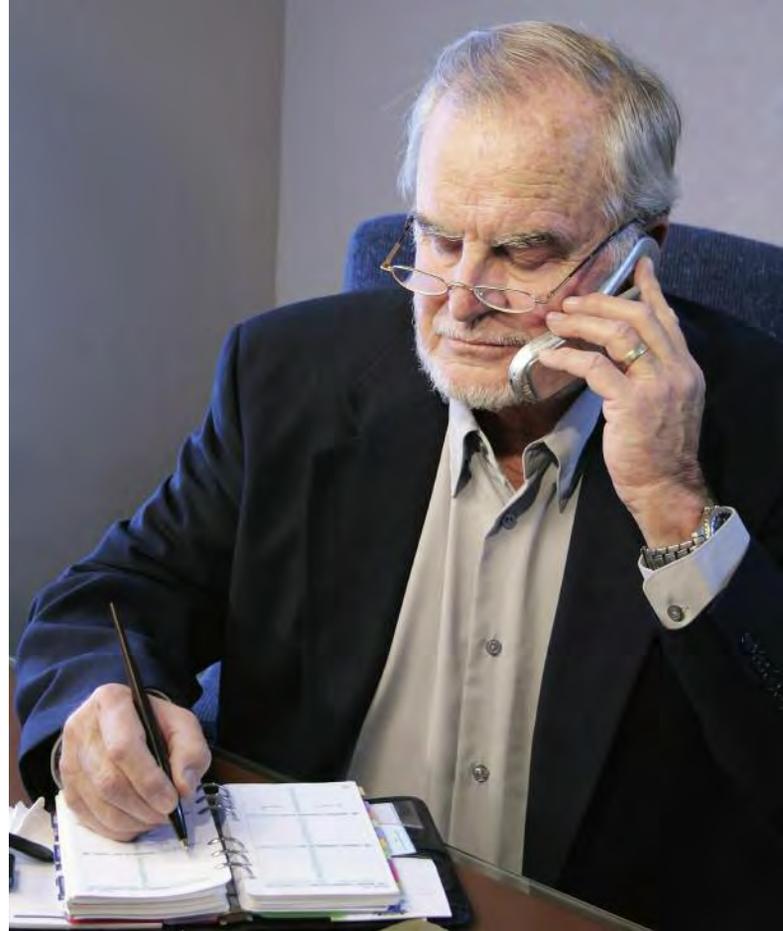
When faced with the large bills that inevitably come, many patients are tempted to reach for their credit cards. A credit card is happily accepted by most providers, but interest payments on the charges increase the amount of the bills. Instead, patients should ask their providers if they will work out a payment plan. Many providers are happy to set up a payment plan with little or no interest, as long as the patients continue with their service.

Also, patients should ask for discounts. If credit cards or tax refunds are used to pay balances in full, patients should request a cash discount. Providers may say no, but the answer is definitely no if the request is not made.

Bills should be compared with patients' explanation of benefits (EOB) statements. When insurance companies have contracts with providers, providers agree to give a discount to patients covered by a particular insurance. Any amount owed above the contracted rate is supposed to be written off and not transferred to patients. Mistakes happen,

If history repeats, patients will continue to bear the burden of increased premiums and out-of-pocket costs for their healthcare.

however, and it is not uncommon for patients to be billed for things they are not responsible for paying. Patients should not pay any amount greater than what their insurance states that they owe. If there is a discrepancy, patients should copy their EOB and send it to their provider. In return, they should ask for a detailed statement explaining the discrepancy. Patients may also need to call their insurance company to request help working with their provider. And, if patients are not satisfied with the answers they get from either the provider or the insurance company, they shouldn't be afraid to ask for a supervisor. They just need to make notes of the date and time of the call, who they spoke



with and the outcome of the call. In the end, the bill belongs to the patient. So, like anything else of value, they should make sure they are getting what they pay for, and are not paying for anything they don't owe.

Preparation Is the Best Defense

Dealing with a chronic illness can be difficult enough, but the added worry and stress of financial obligations can be overwhelming for patients. If history repeats, patients will continue to bear the burden of increased premiums and out-of-pocket costs for their healthcare. The best defense, however, is for patients to get educated and have a plan in place before they get into a crisis mode. Most importantly, they should not be afraid to ask for help. ■

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How to Cope

By Erika Lawrence, PhD

Living with an immune disease, you need to understand how to get the kind of support you want, need and deserve.

Learning how to ask for help in a way that gets you the kind of help you want is a skill — one that requires practice, just like learning to drive a car. If you've never been taught how to ask for help, or didn't have good role models while growing up, you're not going to be good at it. However, with practice, you can learn to ask for support in ways that help you get what you want.

If you are struggling with depression, anxiety or simply want more social support, you can take specific steps to get the support you want, need and deserve. First, you must be willing to ask for support. Following are three basic steps to help give you the courage to try asking for help and support in a new way that can actually bring you closer with others, rather than creating a burden on them and on your relationships.



Step 1

Figure Out What Kind of Support You Need

If someone tries to help in a way that we don't like, we know it. However, many of us aren't sure what kind of help we actually want. There are four basic types of support:

- Emotional support: "I just want them to listen to me, to be empathetic and stop trying to fix things." Emotional support includes having someone simply sit and listen to you and let you know that they understand. It also includes physical comfort. You may not feel like talking about what is wrong that day, but would like someone to simply be there, sitting on the couch with you, or taking your hand or giving you a hug just to let you know they care.

- Tangible support: "On bad days, I just need someone to help me get dinner made." Tangible support is actual, concrete support with specific tasks. This support can be direct, like driving you to a doctor's appointment. It can also be indirect, which is when someone takes care of tasks you would normally have to complete, so that your time is freed up to take care of yourself. For example, someone might go grocery shopping for you, or take the kids out of the house for a few hours so you can get some rest.

- Informational support: "I need to talk this through with someone before I decide what to do." This type of support can help you think about a problem more objectively or in a new way. It can also help you gather information on a certain topic. However, unsolicited informational support can be the most frustrating, and the most damaging to a relationship. In particular, unsolicited advice is the most common way that people provide unwanted support.

- Esteem support: "I just want them to believe in me." Esteem support occurs when others express confidence in your ability to handle your illness or a particular challenge, or they tell you you're not to blame for your illness or for feeling particularly bad on a given day. When dealing with a chronic illness, esteem support can be unwanted. For example, if you do not feel as if you can handle your situation, and the person tells you you can, that feels invalidating rather than supportive. However, generally speaking, you can never get too much esteem support.

The key is to understand the kind of support you would

like and need to get. Only then can you communicate to other people what you want from them. You may find that you generally want emotional or esteem support. Alternatively, you may not want to talk about how you are feeling but would really like some help around the house once in a while.

Often, people want different kinds of support at different times. It may depend on how you feel that day, or what specific challenges you are struggling with at the time. You also may want different kinds of support from different people — emotional support from a friend and tangible support from a co-worker, for example. There also may be times when you simply want to be left alone. Regardless of the type of support you want, the key is to recognize what kind you need and then let the other person know.

Step 2

Get the Support Provider on Board

Becoming good at asking for help is an important skill. But, the other person needs to be able to provide that support as well.

"My family and friends do not understand my situation and special needs."

"They just don't get it because they don't see me regularly."

"They don't get it because some days I seem fine and others I don't."

"They think I am a hypochondriac."

"They think I just need to eat healthier."

Sometimes family members, friends and other loved ones are empathetic, caring people, but they simply do not understand the fluctuations of an immune disorder, or that you are ill even though they cannot "see" it. The trick is to set

a time to have a calm, rational, objective conversation about your illness with them. Think of this as an opportunity for you to help them. Your goal is to talk about your illness and what it is like for you in a way that they can understand. Communicate only as much about your experiences as they seem able to take in. People often get overwhelmed at some point, so you will likely not be able to tell them everything at once. Encourage them to ask questions. Stop and check in with them throughout the con-

Often, people want different kinds of support at different times.

versation to see what they're thinking and feeling. Keep the focus on them and on helping them better understand what your life is like. Only offer reading material if it is requested.

Step 3

Help Others Give the Kind of Support Needed

"When I'm in pain, how can I make my wife understand that this is not a good time to talk?"

"They keep offering advice, but I don't want it."

"Some days, I just want to be left alone, and they just don't get it."

Being good at providing support and help is also a skill that needs to be learned. It's not about providing support, but providing the right kind of support — the kind of support you want, not the kind they think you need. In other words, they need to follow the Platinum Rule: Do unto others as they would have you do unto them.

The most common complaint I hear is that people are giving unwanted advice (informational support). They think they're being helpful, and that you're just "not grateful" for the help. In most cases, people really want to be helpful. Their heart is in the right place, but they're just not good at providing you with help. So what can you do?

First, recognize that their intentions are good. They're not trying to make you feel invalidated and they're not necessarily unempathetic. They just need to learn a new skill. And when you talk to them, acknowledge and express appreciation for their efforts to be helpful and supportive. If you start off frustrated with them, or the person can tell that you think they're not a supportive, empathetic person, they will shut down and not change their behavior.

Second, tell them exactly what kind of support you want. Talk about how their kind of support makes you feel, and what you would like instead. If you give people specific suggestions about what you want, they are usually happy to do it.

Third, give them the opportunity to try this new way of helping you, and thank them for their efforts to change

their behavior. Again, it takes practice, so they won't be perfect at it the first time. Keep practicing.

Keep the Support Going

Now the trick is to keep this communication going. In general, make sure that the relationship has some give and take. In addition to times when you need support from them, there should be times when you support them, even if it is just asking how they are and listening to the answer. Try letting them complain about something going on in their lives, even if it pales in comparison to what you're going through. Similarly, make sure the relationship is balanced between times when you are talking about problems and needing help, and times when you are simply having fun and enjoying each other's company without any mention of your illness or of needing any help.

There are many obstacles to getting the kind of help you need and deserve, and these are but a few. Try out some of these strategies. We all deserve to be listened to and supported. ■

Being good at providing support and help is a skill that needs to be learned.

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Exercise and Immune Disease



Even patients with immune diseases can reap benefits from exercising. Just make sure you are doing enough — but not too much — to ensure optimum health.

By Matthew David Hansen, DPT, MPT, BSPTS

“**W**hat can I do to exercise?” and “Is exercise safe?” are two questions frequently asked by individuals living with immune disease. Unfortunately, with more than 150 primary immune deficiency diseases (PIDDs) and 60 autoimmune diseases (AIs) recognized by the medical community, there is no simple answer. However, almost without exception, we all can — and in fact should — perform some type of regular exercise.

Proper and regular exercise has been proven to help improve mood, self-esteem and intimacy; manage weight and cholesterol; boost energy and concentration levels; promote a better night’s sleep; decrease pain and stiffness; increase strength, endurance and function; combat high blood pressure; prevent the formation of secondary chronic diseases, such as osteoarthritis, coronary heart disease, certain types of cancer and type 2 diabetes; and, in many cases, reduce disease activity. Conversely, a number of studies have demonstrated that physical inactivity significantly contributes to the debilitation and disability that can be associated with PIDDs and AIs.

Scientific literature exists on the benefits of certain types of exercises, as well as the recommended precautions to be taken, for a few autoimmune diseases (e.g., multiple sclerosis and rheumatoid arthritis), but precious little has yet been published for the majority of PIDDs or AIs. Consequently, and because a person’s response to a given

disease or secondary health condition is unique, physical activity should always be prescribed on an individual basis. Nevertheless, there are several guidelines and principles regarding exercise for individuals with PIDD or AI that are global in application.

Consulting with a Physician

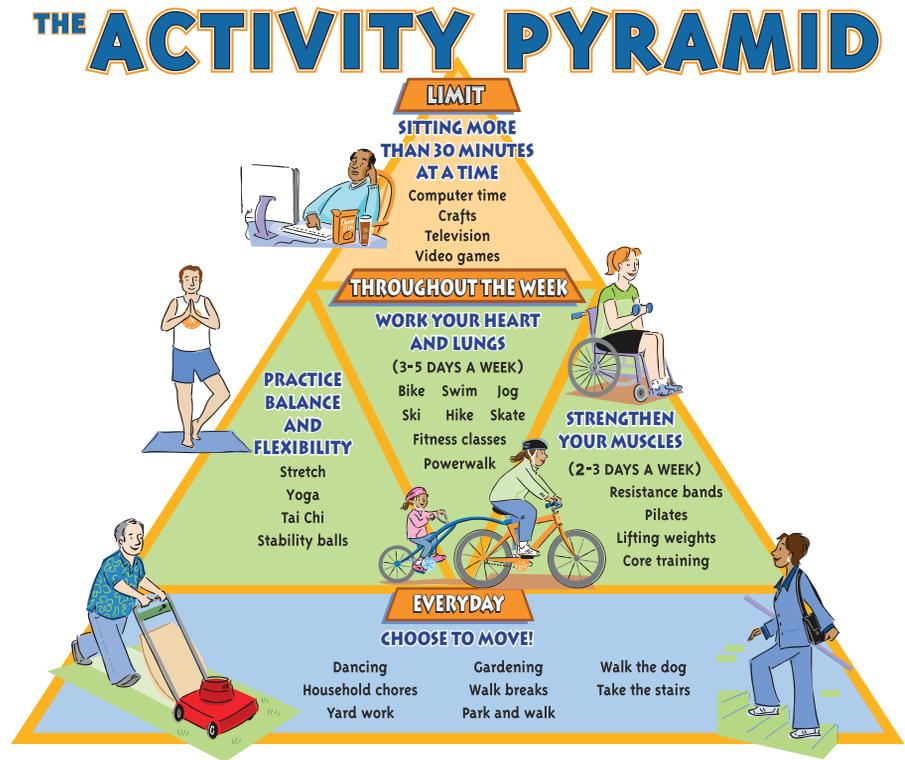
Individuals should consult with their doctor before beginning an exercise program. Physicians will have the best understanding of each patient’s specific condition and of what special precautions should be considered. Some doctors may feel comfortable helping to set up a program. If not, they can refer patients to a physical therapist with a background in treating chronic diseases. It

should not take more than one to three visits for the therapist to get to know the patient and their needs, and to set up a program. Once a program has been established, individuals should check in with the therapist or a qualified athletic trainer or exercise physiologist at least every six months (or any time there is a significant change in health) to reassess the program. If patients experience severe or lasting pain from any of the activities, or a notable exacerbation of symptoms, they should discontinue the activity and contact their doctor immediately.

Choosing a Suitable Exercise Program

Regardless of a patient's current situation, there is almost assuredly an exercise program that will improve their physical, emotional and/or mental well-being. Even those individuals who are experiencing an uncontrolled or advanced disease state may be able to benefit from breathing exercises or assisted strengthening exercises. We need to change the preconception that, unless we are running a 5K or doing 100 sit-ups at a time, we're not exercising! Perhaps running competitively in races is one person's reality, but for many others, it is not. Many patients enjoy the benefits of exercise by taking daily walks, lifting soup cans while sitting on the couch and watching the evening news, blowing up balloons to make animal caricatures or to simply release them into the air, etc. Countless exercise options exist to meet an individual's current abilities, needs and interests.

The correct healthcare professional can help a patient select suitable activities to include in their exercise program, as well as prescribe the appropriate frequency, duration and intensity. The Activity Pyramid (see Table 1) is analogous to the USDA's Food Guide Pyramid, and provides some general guidelines for activity levels. According to the pyramid, an activity plan begins with daily activities at the bottom of the pyramid, which include lifestyle changes (e.g., taking extra steps in your day by walking the dog, taking the stairs instead of the elevator or parking the car farther



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away and walking), and is a great place to begin for those who haven't exercised much in the past.

The pyramid's second level consists of aerobic or recreational activities that should be performed three to five times a week (e.g., long walks, biking, swimming, tennis, basketball and racquetball). And, the third level is made up of leisure activities and strength activities that are recommended two to three times a week (e.g., golf, yard work, bowling, weightlifting, yoga, push-ups/sit-ups). These are examples only of possible activities, and any physical exercise should be cleared with the patient's physician first. All levels of the pyramid can be adapted to an individual's needs. A healthcare professional and/or an occupational therapist may be able to help you find a way to make accommodations or adaptations to allow your participation in a preferred activity that you previously believed was no longer possible. The top level of the pyramid suggests activities that individuals should cut down on (e.g., watching television, playing video or computer games or sitting down for more than 30 minutes at a time without a movement break). The point is to get moving and have fun doing it!

Patients looking for somewhere to start their program

should consider several aerobic exercises that reduce the stress on the joints (and are generally safe for most people). These include stationary biking; walking on even terrain or a treadmill; and swimming, water aerobics or wading. Individuals should stay away from public swimming sites if they have any open sores to avoid increased exposure to

Regardless of a patient's current situation, there is almost assuredly an exercise program that will improve their physical, emotional and/or mental well-being.

infection. Another possible starting point may be with an individual's own family. Many PIDDs and AIs are inherited, or at least have a genetic component. If a family member has the same or similar diagnosis, they may have discovered what type of exercise has worked for them. Even if they have or haven't been actively exercising, this may be an opportunity for family members to get started on a program together.

Keeping Motivated to Exercise

Individuals should take an active part in designing their exercise routine because it increases motivation and improves follow-through. If they choose activities that are of interest or can include a hobby into the mix (or learn a new one), they are much more likely to be faithful and committed to the program. Other ideas to help boost exercise motivation include:

- exercising with a friend and making it a social event
- incorporating exercises into their daily routine (many exercises can be done while sitting at the computer, watching television, performing housework, standing in line at the grocery store or even brushing their teeth)
- keeping a personal exercise log to track improvements
- listening to music, reading a book or learning a language while working out
- buying workout clothes that make them feel good

- rewarding themselves for meeting their exercise goals (as long as the rewards aren't contra-beneficial, such as a big milkshake or chocolate cake — or so large, that they become difficult to keep up with!).

Staying Injury Free

A key to exercise adherence is not to overdo it and to be flexible. The old saying, "No pain, no gain," is exactly that — old advice — and should not become any individual's personal exercise mantra. Many medical professionals consider the jury still out on whether the inflammatory response that can occur with intense, prolonged and/or new exercise exacerbates PIDD or AI activity, although a number of studies conclude that it does not. However, other negative consequences can occur. Overuse or over-extension injuries and exhaustion are common results of pushing too long or too hard and can lead to further disability or complications. At the very least, overuse injuries and exhaustion will almost assuredly affect your daily routine and activity level.

Acute, sudden pain during exercise (that may be accompanied by swelling and/or bruising) is usually indicative of a muscle strain or sprain. The activity causing the pain should be discontinued and the injury attended to immediately. The acronym RICE (Rest, Ice, Compression and Elevation) is the most common treatment response for this type of injury; however, treatment might need to be modified based on an individual's condition. For example, some people can experience a flare-up of symptoms or other negative responses to either cold or compression therapy modalities. If an individual suspects that an injury may be more severe, or if they have a bleeding disorder, they should seek immediate medical attention.



Muscle soreness or stiffness that is felt 12 to 48 hours after exercise is referred to as delayed onset muscle soreness (DOMS) and is probably the result of micro-tears in the muscle. As a general rule, this type of muscle soreness should not be excruciating (though it may be very uncomfortable), should decrease in intensity over time and should not last longer than four to seven days after the activity. If it does not meet these expectations, the exercise needs to be modified or substituted for a comparable activity, and the patient's body may need a short break from its routine until the discomfort subsides completely.

Individuals at greatest risk for "over-doing it" are those who have, for the most part, been previously sedentary and are just beginning to feel the beneficial effects of exercise, those who have recently developed or been diagnosed with a PIDD or AI and are still learning how to manage their care, and the age group consisting of teenagers to young adults (who are more prone to a feel-



ing of invincibility or — at the very least — desire to keep up with their friends). In contrast, the middle-aged and older adult groups tend to be less active than they should, and may be in danger of developing complications of inactivity. Initially, it may be difficult to tell the difference between exercise-induced soreness and the disease-related process. In this case, an individual should begin their routine slowly and pay close attention to their body's response. If they are experiencing an exacerbation of symptoms, or have an infection, it is all right (and may, in fact, be recommended) to decrease or even temporarily

discontinue their exercise program. Yet they shouldn't remain out of the game too long, but rather ease back into it!

A special word of advice should be shared with those

A key to exercise adherence is not to overdo it and to be flexible.

who feel well enough and are determined to run the long races, hike the mountain peaks and train hard, after already having consulted their physician. There is ample evidence to imply that anyone is more prone to developing an upper respiratory tract infection for the first one to nine hours after acute bouts of prolonged, heavy endurance exercise (due to the suppressed function of certain immune system mechanisms). If an individual does decide to participate in more strenuous exercise, medications should be monitored more closely and precautionary measures against infection (e.g., keeping hydrated, but not drinking from someone else's bottle) should be taken.

Any Exercise Is Worth the Effort

Individuals not currently participating in an exercise program should understand the many potential benefits of doing so, and they should speak to their physician about getting started. It does not necessarily take much effort to make an improvement in well-being and quality of life. Even if an individual doesn't yet know the answer to the question, "What can I do to exercise?" after reading this article, they should now know where to start.

As a common expression reminds us, "Excuses are a dime a dozen," but in this case, the benefits of exercise can be absolutely priceless. Whether beginning a program helps to prevent a secondary, and potentially mortal, condition like coronary heart disease, or simply makes a better night's sleep or more time playing with children or grandchildren possible, it's well worth it. ■

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Influenza

The Domino Effect

Patients with immune diseases are at high risk of serious health problems resulting from the flu. And, with the pandemic H1N1 flu emerging along with the already dangerous seasonal flu, it is more important than ever to embrace the concept of “herd protection” to halt the chain-reaction spread of influenza.

By Ronale Tucker Rhodes, MS,
and Amy Scanlin, MS



Each year, influenza affects from 5 percent to 20 percent of the population, claiming 30,000 to 40,000 lives and requiring hospitalization of more than 200,000 in the U.S. alone. Globally, the death rate exceeds 500,000. And, a study conducted by the Centers for Disease Control and Prevention (CDC) found that there is an upward trend in the rates of flu incidence.¹ The death rate between 1972 and 1992 doubled in just 20 years — an especially alarming trend considering in 1997, flu vaccine coverage had reached 65 percent of those most vulnerable. The intensity of flu epidemics is also increasing. In the 1970s and 1980s, the

average length of an epidemic period was 8 to 10 weeks. Today, it is closer to 16 to 18 weeks.² Add to this the new pandemic H1N1 flu, and the number of people who contract the flu this season stands to be far greater than the world has experienced in a very long time.

One of the primary reasons the spread of flu continues to be prevalent is that not enough people get vaccinated. Individuals who have immune diseases should be especially concerned, as they are most at risk of serious health complications resulting from the flu. Educating people about how the flu spreads and convincing them to adopt a herd protection mentality could help immune-compromised patients, as well as the rest of the population.

Adopting Herd Protection to Halt the Spread

For years, the main thrust of flu vaccination campaigns has focused on the very young and the elderly. This emphasis may be misplaced since the immune systems of the old and infirm don't always respond efficiently to the flu vaccine, nor



are these populations usually responsible for spreading the virus. Some suggest that a better tactic may be to focus vaccination efforts on healthcare workers, school-age children and working adults — those who consistently come in contact with others and are more likely to infect others. Embracing this concept, called “herd protection,” has its roots in the idea that you protect the weakest members of a flock by strengthening the defenses of its strongest members and, in doing so, bolster the herd’s communal defenses.

Paul Glezen, MD, Baylor College of Medicine, Houston, Texas, is one of a growing number of physicians who subscribe to the idea of herd protection with regard to vaccinations for the flu virus. Glezen argues that focusing vaccination efforts on the very young and old, which is the current recommendation, is less effective because these people, while most susceptible to the effects of the flu, are not in contact with mass numbers of the population, and, ironically, may not respond as well to the vaccine. According to Glezen, herd protection is a well-established concept and a reasonable approach to a systematic immunization program.³

Another benefit of the approach is that school-age kids and working adults, because of their need to congregate in schools and the workplace, are accessible populations for rapid deployment of the flu vaccine and, in turn, offer the greatest chance for success for the vaccination to actually reduce the incidence of flu in a community.

There are many examples of herd protection working. In a Japanese study from 1977 to 1987, it was mandatory for school-age kids to get the flu vaccine. Most households in Japan at that time were three-generation households and the flu vaccine was not given to the elderly or high-risk. Japan saw a reduction in flu-related mortality of 35,000 to 47,000 per year.⁴ Incidentally, after 1987, due to parental concerns about the vaccine being mandatory, the program was ceased and the death rates from the flu reverted back to pre-program levels within a few years.

In the U.S., an ongoing program in Temple, Texas, near Austin, is also proving the herd protection strategy a most effective one. Starting in 2001, school-age children have been receiving the yearly LAIV flu vaccine, and preliminary data from the 2005-2006 school year showed almost no incidents of influenza. In the 2008-2009 school year, Temple, Texas, has so far escaped the flu again, while

nearby cities have had large outbreaks that resulted in school closures, hospitalizations and even deaths.

Vaccinations for Healthcare Professionals

The recommendation of vaccinations for healthcare professionals (HCPs) and those in training is also part of herd protectionism. HCPs are in close contact with those with primary immune and autoimmune diseases, as well as those with decreased immunity — the sick, the young, the old — and even when they have subclinical presentation of the influenza virus, they can spread it. With most on the front line of patient care sharing the physician’s Hippocratic oath: “Do no harm,” it is puzzling to learn that nearly 60 percent of American healthcare workers fail to get an annual flu shot. “I’d like to think we [HCPs] get vaccinated because it is the right thing to do,” says Dr. Andrew Eisenberg, medical director at the Iron Mountain Medical Center, Madisonville, Texas. “We have an obligation to not get patients sick. The mortality and morbidity rates are less at hospitals where vaccination of workers is mandatory.”

Fifteen states have regulations regarding vaccination of HCPs in long-term care facilities, six states require that healthcare facilities offer influenza vaccination to HCPs, and four states require that HCPs either receive influenza vaccination or indicate a religious, medical or philosophical reason for not being vaccinated.⁵

Despite the availability of vaccines, healthcare workers consistently fall short of immunization goals.

While U.S. statistics regarding healthcare worker immunization are well below the goals established by Healthy People 2010,⁵ international statistics are even less encouraging. In England, only 14 percent of healthcare workers were immunized before the 2008-09 flu season. An article published in the *London Times Online* states that the Royal College of General Practitioners in England recently called for hospital doctors, general practitioners, nurses and other staff to have compulsory flu shots or risk being banned from patient contact.

USA Today reported that the National Foundation for Infectious Diseases cites several cases of flu outbreaks that suggest a likely link between healthcare workers and patients. These include:

- 19 babies in a neonatal intensive care unit in Ontario, Canada, infected in 2000; one died. Healthcare workers, only 15 percent of whom were immunized, were the likely source.
- 65 residents of a nursing home in New York got the flu during the 1991-1992 flu season, and two died. Only 10 percent of healthcare workers had been vaccinated before the outbreak, according to a report by the CDC.

And in England, *The London Times* reported that at Royal Liverpool University Hospital, nearly 100 patients caught the flu in late 2008, including those on high-dependency wards treating blood diseases and kidney problems.⁵

Vaccinations: Changing Perceptions of Who and How

The CDC's Advisory Committee on Immunization Practices (ACIP) makes best practice recommendations for administering the flu vaccine.⁶ Among those recommendations are:

- The annual vaccination is to be administered to all children ages 5 to 18 years.
- The annual vaccination of all children ages 6 months through 4 years (59 months) will continue to be a primary focus of vaccination efforts because these children are at higher risk for influenza complications compared with older children.
- Either trivalent, inactivated influenza vaccine or live, attenuated influenza vaccine (LAIV) will be used when vaccinating healthy persons ages 2 through 49 years.

Now, with the H1N1 flu season upon us, the CDC has given priority for the H1N1 flu vaccine to approximately 159 million persons in the U.S.⁷ These include:

- Five million pregnant women
- Four million parents and caregivers of children younger than 6 months old
- Fourteen million healthcare workers
- One hundred and two million people between ages 6 months and 24 years
- Thirty-four million adults between ages 19 and 64 with chronic diseases

While it is nearly universally accepted that we will never be rid of the flu virus, we can do a better job of helping

our population build antibodies to protect against it, as well as protecting those most at risk from it. "In my view, we have not done a very good job of vaccinating, and the biggest problem that I see is mixed messaging," says Eisenberg. "We've developed rules and procedures as to who is most at risk and [who] should be vaccinated, but everyone is at risk of catching this disease. The success of our vaccination strategy will hinge on getting a large penetration of the population immunized."

A child with severe combined immune deficiency will not benefit from any vaccines and could be harmed if given a live virus or bacterial vaccine.

Many choose not to get the flu vaccine, and young healthy adults are chief among them because they feel they are not at high risk, that the vaccine doesn't work and/or they think that getting the flu vaccine will make them sick. Clearly, more education, communication and effort are needed to help dispel some of these common myths surrounding vaccination to ensure it is more widely embraced through our culture.

Vaccination Safety for Immune Disease Patients

A common concern is whether the influenza vaccine is safe. And, while the flu vaccine is not only safe, but recommended, for most patients with an immune disease, for each of the more than 100 types of immune diseases, their response to vaccinations may be different. For example, children with B cell problems have diminished antibody response to vaccines. A child with severe combined immune deficiency will not benefit from any vaccines and could be harmed if given a live virus or bacterial vaccine.⁸ Patients with Guillain-Barré syndrome (GBS) and chronic inflammatory demyelinating polyneuropathy (CIDP) are cautioned about the possible risk associated with the flu vaccine. GBS has been known to be triggered by flu shots. According to the ACIP, whether influenza vaccination specifically might increase the risk for recurrence of GBS is unknown, persons who are not at high risk for severe

influenza complications but who are known to have experienced GBS within six weeks generally should not be vaccinated.⁹ According to Dr. Todd Levine, director of the department of neurophysiology at Good Samaritan Hospital, Phoenix, Ariz., “Patients with CIDP have an overactive immune system, so in general, we do not want to stimulate their immune system. Flu shots do just that, so I usually recommend patients not get flu shots.”

For patients for whom flu vaccine is safe, they should know that the injectable vaccines that have been created to help prevent both the seasonal flu and the H1N1 flu are inactivated, meaning they are killed. Inactivated vaccines are different from live vaccines that are made from live viruses or bacteria that have been weakened. Live vaccines, such as FluMist, have a possibility of causing the disease itself, especially in primary immune disease patients who lack the immune defenses necessary to fight certain diseases. Inactivated vaccines, on the other hand, are made from viruses or bacteria that have been killed, and therefore, cannot cause the disease that it is given to prevent.¹⁰

Whether flu vaccine is safe or unsafe for certain immune disease patients, it is important that family members, friends and co-workers of this population be vaccinated to prevent infecting them. And it's essential for those who come in contact with patients who are unable to be vaccinated.

Improving Access and Distribution — Just Part of the Solution

Multiple companies manufacture flu vaccines, and there are increasing numbers of vaccine administration sites — from physician offices and retail pharmacy outlets, to schools and the workplace. If utilized, ample supply and efficient administration will protect large numbers of people in a short amount of time and reduce our rates of infection. Says Eisenberg, “Even if we can get 60 percent vaccinated, we'll protect that 40 percent who either shouldn't or won't be vaccinated.”

It's important to remember that seasonality is a misnomer when it comes to the flu, because the flu is always circulating throughout the globe year-round, mutating, infecting and, in many cases, killing those who are not vaccinated or treated in time. Accurate diagnosis is also necessary if we are to effectively win the battle against the flu virus. “We have a diagnostic problem,” says Eisenberg, referring to the U.S.' ability to determine whether a person has the flu and, if so, what strain they have. “Our tests are sensitive but not too specific, and we don't have a great test to determine the strain. Many can have a relatively mild case of the flu,

though not be identified as having it because they confuse the flu with something else.” Misdiagnosis is a problem because as people are sent home from emergency rooms and doctors' offices, they are inadvertently spreading the flu when they should be isolating themselves.

Vaccination of the Fittest for the Survival of All

We live in a uniquely egocentric time. For many, looking out for “number one” is a way of life that is rarely questioned. When it comes to influenza control, however, a “live and let live” mentality translates to: “Infect and allow to infect.” Better to reorient the national consciousness so the strong and active segments of the population step up to be immunized to protect themselves, and give indirect protection to the vulnerable. This shift may offer the most efficient and effective use of the influenza vaccine. And with the threat of a pandemic ever looming, our very survival may depend on it. ■

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Let's Talk!

By Shirley German Vulpe, EdD

If your life depends on immune globulin, this column is for you! Here, we have an opportunity to network and share our experiences about all of the ramifications of our illnesses, and to learn from one another. If you have a question, comment or experience to share for a future column, email it to us at editor@IGLiving.com.

Joanne Lund is a 46-year-old woman with two sons — Nick, 16, and Danny, 9 — both of whom have pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS). PANDAS is a rare autoimmune disease that occurs after a streptococcal infection, and affects children as young as 15 to 18 months old. It is an easily misunderstood condition that is often completely missed. A history of other conditions such as Sydenham's chorea (St. Vitus' Dance), sudden onset

motor and math skills and obsessive compulsive behaviors such as repeated hand washing, intrusive thoughts, anxiety, unfounded fears and phobias. Initially, symptoms subside after antibiotic treatment but reoccur and get worse and last longer with each infection. If not treated before adolescence, by age 14, the neuropsychiatric symptoms may remain. Treatment recommendations include long-term prophylactic antibiotics, prednisone and intravenous immunoglobulin (IVIG). Some

diagnosed when he was 8, but he had been showing signs of PANDAS since his first streptococcal infection at 4 years old. My youngest son, Danny, was 5 when he first showed symptoms of PANDAS. The diagnostic process and getting the correct treatment was a nightmare. I took my Nick to his pediatrician when he developed severe behavior problems in second grade. Blood work indicated a streptococcal infection, and he was given antibiotics and recovered. But in six months, he was ill again, with horrible nightmares, fears and tics. He then had his tonsils removed, which helped until he got sick again, this time with much worse behavioral difficulties.

I filled out forms documenting his behaviors for two years, and it was determined that Nick met all the criteria to be admitted to a PANDAS clinical trial. At the end of the trial, he was to be administered IVIG, but the study lost its funding. I tried everything: contacted doctors, pediatricians, neurologists and immunologists, wrote all of our representatives and senators, appealed to the insurance company, researched on the computer and sent copies of pertinent information to our pediatrician's office. I was finally able to get a doctor at one of our hospitals

“Nick met all the criteria to be admitted to a PANDAS clinical trial ... but the study lost its funding.”

Tourette's syndrome and/or obsessive compulsive disorder and anorexia nervosa may be present. Neuropsychiatric symptoms appear suddenly, often overnight, and can include tics, separation anxiety, anorexia with a fear of choking on food while eating, enlarged pupils causing patients to look frightened, hyperactivity, a significant decrease in fine

neuropsychiatric drugs such as Haldol and selective serotonin reuptake antidepressants can cause a negative response and are, therefore, not recommended for symptom management.

Shirley: When were your children diagnosed, and what happened during the diagnostic process?

Joanne: My oldest son, Nick, was

to order IVIG for Nick. After two weeks, his improvement was incredible, but the doctor declined to follow him. So, Nick had a couple of wonderful months and then he got sick again. He would not eat, had nightmares and saw ghosts. All diagnostic tests fit the criteria for IVIG treatment, but the hospital refused to administer it, the doctor refused to prescribe it and the insurance company refused to pay for it. I found out later that the hospital had never been paid for Nick's first infusion.

Then, my Danny got sick, and his pediatrician was not helpful. At our wits' end, we found a specialist in Chicago who agreed to see the boys. He recommended IVIG and offered to get it for the boys, but he told us that our insurance company would not pay for out-of-state treatment.

Shirley: Where did your children eventually receive IG?

Joanne: After many tries, we were able to find an immunologist who would prescribe it, although he would not have it administered in a hospital, which is the safest place for a first infusion. We also were able to find a specialty pharmaceutical company to supply IG, as well as a nurse to administer it in our home.

Shirley: Has IG helped?

Joanne: Definitely. I now have two healthy, socially adept, wonderful boys. Nick still has a few residual tics because it took so long to get the correct treatment, but Danny has had a complete recovery.

Shirley: Have you received any support?

Joanne: My husband, my mother, two nurses, as well as Hillary Clinton and her office staff. Our finances were very strained by all the medical

Resources

1. Webpediatrics.com:
<http://www.webpediatrics.com/pandasclinicalcases.html>
2. National Institute of Neurological Disorders and Stroke
Sydenham Chorea Information Page:
<http://www.ninds.nih.gov/disorders/sydenham/sydenham.htm>

costs. However, my husband and I agreed to go ahead with the IVIG treatment and charge it to our credit card. We had agreed to mortgage or sell our house if needed. My mother had a garage sale to raise money. The nurses read the information I sent to the doctor's office, supported my descriptions of the changes in my children's behaviors after an infection, and helped me carry my son into the doctor's office as he grabbed a chair when he had been refused an appointment. When Hillary Clinton was a senator, her office had a special section to handle health insurance claims. I had written to all of our representatives and senators, and her office was the only one that responded. By coincidence, on the day that the nurse came to the house to give Nick the IVIG, her office called me. They asked how we were managing, and I told them the whole story. They said they would do everything they could for us. They called the hospital, the doctors and the insurance company. We were reimbursed our costs by the insurance company six months later.

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

Joanne: To use Haldol for Nick. It is contraindicated in PANDAS and can cause severe problems.

Shirley: What was the best advice?

Joanne: The medical specialist in Chicago who saw my children and said IVIG was the best treatment for them suggested we do everything we could to get IMG in our own state. So that's what we did.

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

Joanne: Follow your heart. You know your child best, including the symptoms they have and how they have or have not changed as a result of treatments. Research and do everything you can on your own. Do not listen to anyone who says nothing can be done. ■



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

Ask Kris

By Kris McFalls

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

Allison: My son is an avid vegan and is extremely health conscious. He insists that if I eat a diet free of meat and eggs and high in vegetables and fruits, my body can correct itself of common variable immune deficiency (CVID), as well as any other disease or illness. I am a nurse and have extensively researched immune deficiencies, and while I understand that eating a healthy diet and exercising is something we all should do, I do not believe that an immune deficiency can be "corrected" through a diet. Would you please answer this question so that my son doesn't continue to think that I am making myself ill?

Kris: Eating healthy and getting an appropriate level of exercise is key to optimal health. However, if an immune deficiency could be cured with a healthy diet, doctors would not prescribe immune globulin (IG) and insurance companies would not pay for it. It is not uncommon for patients in the IG community to encounter well-meaning friends and relatives offering advice about taking certain vitamins and supplements. Their motivation is usually out of love and the desire to help. If only it were that easy. I asked *IG Living* advisory board member Dr. Erika Lawrence to address your concerns.

Dr. Lawrence: It can be frustrating when people give unsolicited advice, and even more frustrating when they expect you to follow it. This frustration

can make it hard to remember the person's intent for offering the advice. In this case, your son is presumably coming from a place of love and caring, and truly wants to help and be supportive. Unfortunately, his way of attempting to be helpful is backfiring.

When someone gives unwanted advice, many people fall into the trap of arguing with the advice giver. Unfortunately, this approach rarely stops the other person from giving that advice, and it usually hurts their relationship with the person. So what can you do instead?

1. Ask him to stop giving advice in a respectful way. It is critical to be able to ask for the kind of support you want in a respectful way, so that you don't invalidate your son's efforts. If you ask for support in a manner that is disrespectful, sarcastic or critical (e.g., "Why don't you just listen to me rather than always trying to give me advice?"), your son may simply withdraw and stop trying to help altogether (rather than simply changing the way he tries to help). A more respectful approach would be to say, "I know that you are encouraging me to become vegan because you think it will help with my health problems. I know you have good intentions. However, it really upsets me when you do that, and it's affecting our relationship."

2. Provide an alternative way for him to help. Be specific when you tell your son what kind of support you want, rather than telling him what type of support you don't want. Taking a positive approach, what would you like

him to do? Listen and be empathetic? Help you with tasks around the house when you're not feeling well? Distract you from your health concerns? Not ask you about your health at all? By providing a specific alternative, he has something to do when he wants to help.

3. Thank him for trying a new way of helping. Let's assume that your son tries to help you in a new way. The way you respond to his efforts plays a big role in whether he will continue to support you in this way in the future. If you respond by criticizing him for giving you advice in the past, your son will be less motivated to continue this new way of helping you in the future. Instead, express appreciation for responding to your request that he stop giving advice. Your son may not be perfect at helping in a new way at first, but if you reward his efforts, he is far more likely to keep trying. More importantly, he is far less likely to go back to arguing with you about whether a vegan diet can cure your CVID. ■



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.



ERIKA LAWRENCE, PhD, is an associate professor of clinical psychology at the University of Iowa, and has a private practice in which she works with individuals, couples and families experiencing depression and anxiety symptoms or simply learning to cope with stress.

Prednisone: My Stalker

By Ever Fecke

I HAVE SOME exciting news! After dating my boyfriend, Jim, for five years, he has asked me to marry him! I am so excited, and the planning has already begun. Yet, I feel as though I have consumed myself with all of the details of planning our big day to try to distract myself from the stress of what is really my number one concern: prednisone.

I always imagined myself in a size 8 wedding dress. Not too small, yet realistic and curvy. However, my imagination has completely overshadowed the reality of being prescribed prednisone for four years. I am not even close to a size 8, but more like a size, er, 16. Even my ring size — which was always a standard size 7, the size of every ring found in a jewelry store — has changed. When I opened that beautiful black velvet box to find a classic, stunning princess cut, solitaire engagement ring, I immediately wanted to put it on my chubby sausage-like finger. But, of course, it didn't fit! I had to wait two weeks while it was being resized to an 8¼ to finally squeeze it over the pillow at the base of my finger. I tried to look on the bright side; I had waited five years for this moment, what was another two weeks?

When I close my eyes, the reality of this vicious, yet lifesaving, drug is nowhere to be found. But when I look in the mirror, the effects of prednisone are staring right back at me. Prednisone has become my stalker, lurking around every corner and following me like a bad shadow. The pudgy me has been



tailing the other me through good times and in bad times for the last four years. And, I have to admit that, in the bad times when my lungs are not functioning as they should, it has been nice to have its company. (Sure, this follower that brings so much ambivalence would love the credit for saving my life!) But, when things are good, I wish this devotee to my well-being would just go away.

I imagine what my wedding will be like if I am still on 60 mg of prednisone a day. My dad will roll me down the aisle, or pull me in a wagon to meet Jim at the altar. As the rabbi begins the service, I will have severe hot flashes and episodes of profuse sweating, only to see one of my false eyelashes become unglued. And, as Jim recites his vows, I will look at him in horror and whisper, "I have to go!" and as he replies, "So, go!" I grab my sister's hand (my maid of honor) and we take off running down the aisle

for that porcelain sanctuary where she helps me lift my princess skirt over my head just in time.

My graphic imagination also has allowed me to come up with some solutions to a potentially disastrous wedding day. I could wear adult diapers under my gown since no one will be able to tell under all the frilly tulle. And, I could put a battery operated fan in my garter under my dress to relieve the hot flashes. (Hey, I may just do that anyway!) I'll look like Marilyn Monroe, only rounder and brunette.

I have 14 months until that wonderful day, and I am now being slowly weaned of my evil, clingy shadow. I have made it to 8 mg every other day, and it has only taken me about two months to get here. I have quite a journey ahead of me. I talk to my lungs every day, like a crazy person (thanks to my faithful friend, I'm a little cuckoo), and I tell them to hang in there. We need to look fabulous and we are going to make it!

So, stay tuned. I'll keep you posted on my quest to rid myself of these unwanted pounds and the steroid companionship of that lifesaving little white pill. ■



EVER FECKE 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!

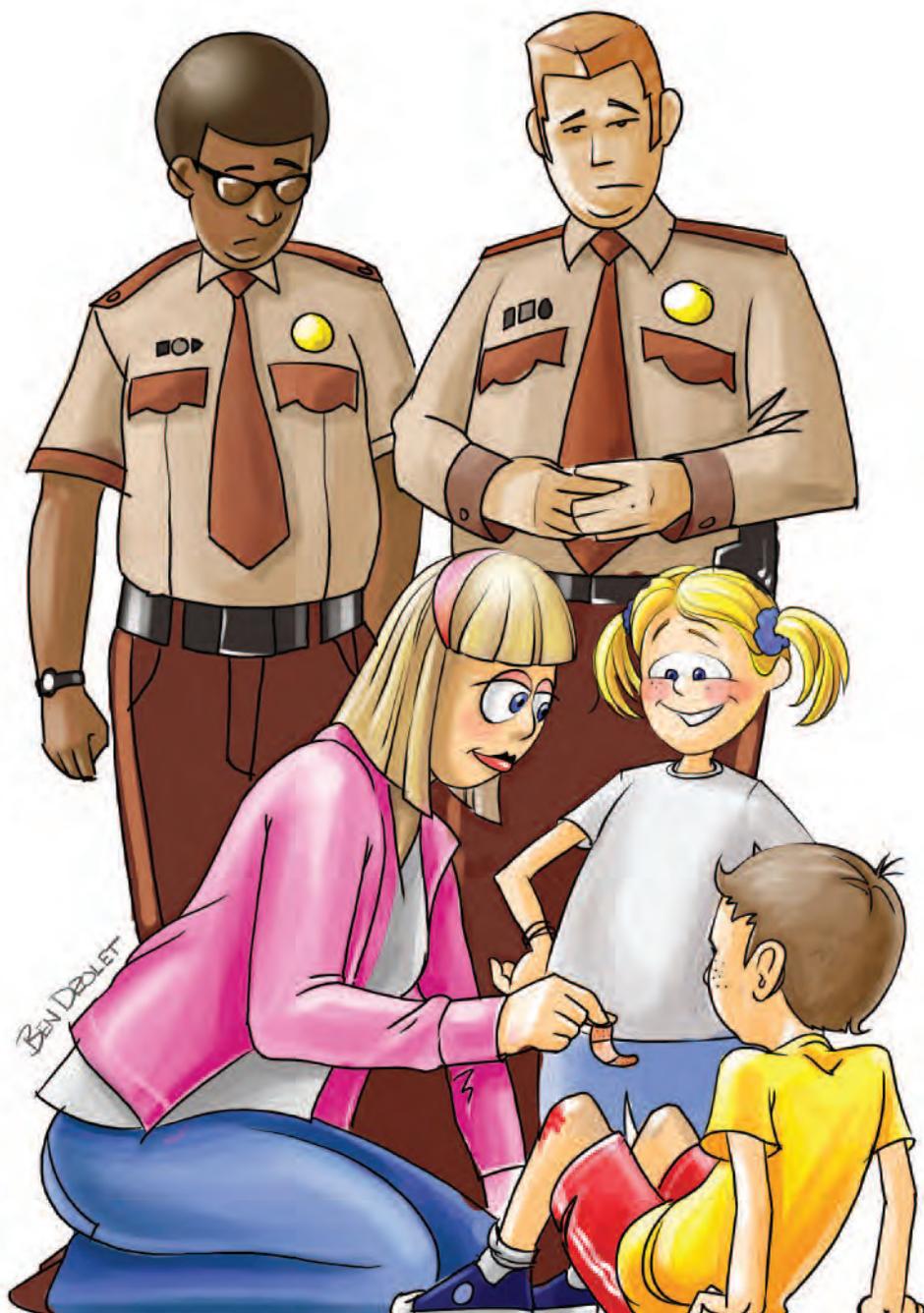
Shop 'til You Drop

By Cheryl L. Haggard

IT WAS A dark and stormy afternoon, and my PIDD kid, Molly, and I were roaming the crowded halls of our local shopping mall, hitting the sales of the impending holiday season. Folks were bustling to and fro with their bargains in hand, some dodging the Twitters, Texters and Tweeteters, whose fingers seem to dance on their beloved cell phones. Navigating the throng, Molly and I dodged the random human bullets, avoiding collisions and potential “miscommunications.” Note to self: Next year, I’ll let my fingers do the walking and shop online!

Our family has been warned by several in the immune deficiency community to avoid public places like crowded shopping malls — a germ farm of sorts. Being females, however, Molly and I felt that would be missing a rite of passage between mother and daughter: to shop all day and all night until my credit cards screamed “uncle” and estrogen leaked from our ears.

The aroma of gingerbread latté and the addictive caffeine rush side-effect energized my senses and seemed to coat my tongue. I grabbed Molly’s delicate hand, one that had experienced the sting of repeated IVs, and gently led her to the coffee shop with its signature half-naked mermaid insignia that always entertains my sons’, Calvin’s and Caleb’s, pre-pubescent eyes. I took out a personal loan and paid for a grande, sugar-free, two Splenda, three pump, skinny, light-



whipped gingerbread latté, two freshly defrosted, slightly warmed chocolate chip cookies and a venti no-ice tap water. I breathed in the luxurious steam from my hot drink and felt Molly and I were finally getting what we dreamed of — a time when we could forget needles, nursing and nasty, never-ending infections. Just by being in a “forbidden place,” we felt normal and a bit naughty all at the same time. Oh, what sweet bliss to be with my Molly, healthy at the moment and doing something so common!

That was until familiar screams ruined my sick-day getaway — the screams I hated more than anything: a child in pain.

“Mom, let’s go see what’s goin’ on!” Molly urged, her chocolaty breath invading my air space. “Maybe we can help!”

My PIDD kid’s request didn’t shock me; Molly has a heart for and relates to kids in desperate pain. In fact, between her and her brothers’ chronic illnesses, surgeries and immune globulin infusions, Molly has a taste for becoming a physician some day. Molly started her career when she brought a cryogenically frozen grasshopper back to life last winter, but that’s another story.

I entertained every idea that popped into my head to relieve me of doing the decent thing and going down the stairs toward the wretched wailing. Can’t I just have one day free from human suffering? I begged, staring heavenward.

When our eyes locked, I saw a sense of urgency in my sweet daughter’s soul. She wanted to help the hurting, even on her day off. Who was I to deny her?

“OK, let’s go, but first I want to gather up...” Before I finished my request to clean up our expensive mess, Dr. Molly was already on her way to the emergency.

Surveying the scene as I headed down the escalator, hot toddy in hand, I began to giggle. Two plump security officers accompanied by a housekeeper with a cart circled around a whimpering boy as if they were three Snoopy dogs looking down at their empty dinner dish. Molly, on her knees, had already given aid and comfort by placing her white sweater (read: “foolish purchase”) under the poor boy’s head.

“Excuse me,” I said breaking up the gawking trio, and entering the circle where the victim lay.

“Oh my, what happened?” I asked the boy’s mom, putting my arm around her shoulder.

Shaking, she managed to tell me, “As he was heading down the escalator, fooling around backwards, a hungry step took a bite out of his knee.”

“See, I told you my mom’d come. She’s a wonderful nurse,” Molly interrupted and half lied to her patient. Except I’m not a nurse, even though I play one at home all the time.

“Oh well, then if you’re a nurse, can you help us?” the freaked-out mom begged.

I didn’t have time to explain my true identity. I suppose because I didn’t puke or pass out after I began to triage the poor kid’s bloodied and exposed kneecap, I was granted a temporary nursing degree.

Creating a mini trauma room on the unsterile mall floor, I barked out orders to the three Snoopys like a pro:

“Get me a first-aid kit.”

“Write down directions to the nearest hospital.”

“Clean up the blood drippings so no one slips.”

“Don’t touch my latté!”

All the while, Molly cooed and comforted the frightened boy.

“I’ve never had stitches before, have you?” Molly’s patient asked. And just like a child-life specialist, Molly answered his questions with truthful tenderness; she even shared her own story about why she had to get needles to stay healthy.

Later, feeling spent from the last hour on the mall’s floor, Molly and I settled into the car and headed for home. We had no packages to jam in the trunk or any bargains to be proud of. The only thing we took home from the mall that day was a big life lesson: ‘Tis better to give than to receive. But, being a good receiver isn’t half bad either! And what we received that day, especially Molly, was a lesson that can’t be wrapped in shiny holiday paper: Molly’s immune globulin infusions made it possible for her to help another toward healing.

“So, did you gals have fun today?” my husband, Mark, asked with a cheeky smirk.

Molly looked at her daddy and said, “Yup! I shopped ‘til I dropped!” ■



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

The Most Wonderful Time of the Year

By Mark T. Haggard



It's the most wonderful time of the year!
With the kids Omnicef sipping,
And the IgG dripping,
Making sinuses clear.
It's the most wonderful time of the year!

It's the hap-, happiest season of all!
When germs are arriving,
Our kids will be thriving,
When friends come to call.
It's the hap-, happiest season of all!

There'll be inhalers for wheezing,
And Zyrtec for sneezing,
So kids can go out in the snow.
There'll be long-winded stories,
And some will be gory,
Of infections from long, long ago.

It's the most wonderful time of the year!
So now thanks to IgG,
This year there will not be,
Holiday trips to ER.
It's the most wonderful time of the year!

It's the most wonderful time of the year!
There are nurses nurturing,
And doctors researching,
So be of good cheer.

It's the most wonderful time,
(Hit the high note) It's the most wonderful time,
It's the most wonderful time,
Of the year!

Happy and healthy holiday greetings
from Mark and Cheryl Haggard! ■



CHERYL L. 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.

Chronic Conditions and Self-Image

Individuals with chronic conditions often suffer from poor self-image, and at times deal with this by denying their illness. But, sustaining a healthy self-image is possible.



By Lauren Gerstmann, MPH

When dealing with chronic illnesses, it is vital to understand the toll that these illnesses can have on self-image. Just ask Laurie Edwards, one of 25 million Americans whose ability to carry out daily activities is limited by chronic illness. (Chronic illnesses — those that either are persistent and lasting medical conditions, or regularly relapse after periods of remission — include diabetes, asthma, osteoporosis, immune deficiencies and autoimmune diseases.)

Laurie, who struggles with an immune deficiency and an airway condition similar to cystic fibrosis, defines herself as a writer, teacher, wife, patient, aunt and friend. According to Laurie, “Every one of those roles is definitely [influenced] by illness.” Laurie is quick to note, however, that illness hasn’t affected her entirely negatively. “I think that I am a very determined person. I think that is because of illness largely. I mean, maybe it would have been

part of my personality anyway, I don’t know, but ... from my early life, I have always had to push back against being sick.”

As Laurie’s words imply, for better or worse, chronic illnesses often shape individuals’ self-image. Some deny the limitations that a chronic illness imposes upon them. Others feel devalued because of limitations caused by a chronic condition. Either way, the end result is clear: Having a healthy self-image while dealing with a chronic condition can be a challenge.

The Sense of Self

The medical community is slowly starting to realize that the emotional effects and frustrations of chronic illness impact patients’ health. Researchers have found that when people view their circumstances as a “loss of core aspect of self,” their quality of life is significantly reduced. In this regard, how someone perceives their situation will greatly affect their self-image, and potentially, their health.

In her book *Life Disrupted*, Laurie talks about the perceived chasm between her sick self and her healthy friends, relatives and co-workers when her illness limits her abilities. She struggles with “this desire to uphold the identity of a healthy

person, while still remaining conscious of what will always differentiate us.”

Kristin Renz, who has myositis, can relate. When Kristin first became ill, she was working part time in a medical office. She was hospitalized for what she thought was an isolated problem, but she has never been able to return to work. “At first, I was too sick to really care,” she says, adding that at times, “I miss working and feel useless as a part of society.”

In truth, however, Kristen recognizes that feeling useless is not an accurate assessment of her self: “It’s usually on my good days that I miss working and bringing home a decent paycheck. On my bad days, I realize I’m not capable of being a productive or reliable employee.” In that regard, Kristin has grasped a key lesson: Her job is to keep well. So although a chronic illness can take up someone’s time, energy and health, it does not need to steal self-confidence or the ability to lead a happy life.

“Chronic illness, if anything, has taught me patience and accept-

ance,” explains Kristin. “I’ve learned that I’m the only one who truly knows what is going on with my body. I ‘listen’ to my body and I react accordingly. I don’t let anyone else dictate what I’m going to do, and I

Having a healthy self-image while dealing with a chronic condition can be a challenge.

don’t let anyone make me feel bad if I can’t keep up. I’m not perfect, though, and I do get frustrated. I also have my down periods [when] I get mad [that I am] sick, but I push through it and move on.”

The Dangers of Denial

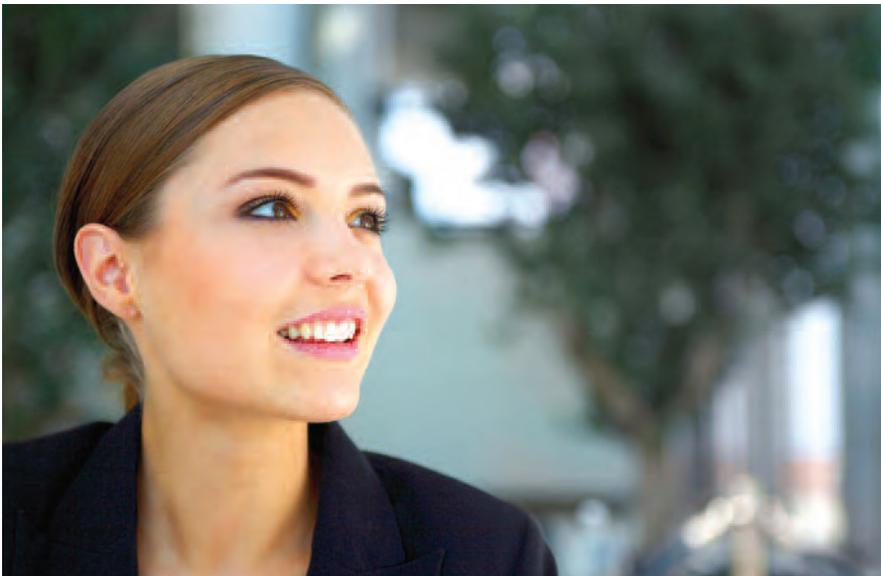
The flipside to individuals with chronic diseases beating themselves up about their limitations is denying them. Laurie knows denial well: “When I was in college, I think that I was more defined by trying to prove that I wasn’t sick than anything else. And that was a very bad cycle to be in.”

According to Laurie, she was either extremely active with taking classes, working 60 hours a week and taking on extra activities, or she was in a hospital bed. “I think I wanted to prove that being sick didn’t matter — that I could do anything that I wanted,” she explains. “But I began to realize that ... I was letting illness define me in negative ways.”

By trying to deny the realities of her illness, Laurie was succumbing to the belief that to admit she was ill would be some sort of failure, as if the admission itself would rob her of her ability to function productively in society. Her tendency is far from unique. Part of the reason that Laurie and others are tempted to deny the limitations imposed by their conditions is due to concerns about being stigmatized, which can be a common occurrence for chronic illness sufferers.

Denial also can be the result of a pragmatic urge. It is time-consuming to be sick! Visiting the doctor can become a job in and of itself if individuals have a complicated medical condition or they need to manage multiple conditions. Maybe, if they deny the illness, they won’t spend so much time on treatment. But, of course, the reverse is true.

Denying an illness can only lead to exacerbations that will take more



time (and more procedures or medication) to manage. So, ultimately, denial can also lead to an unrealistic self-image that may further affect their ability to effectively care for themselves.

It's much better for those with chronic illness to integrate the condition into their lives. Doing so will translate into the healthiest self-image and, ideally, the ability to take an active role in their own care. For example, it is critical for them to communicate effectively with their medical team, so visits actually improve their condition and don't simply add to the demands of being sick. Achieving best health is a team effort between patients and their medical team.

If patients find it difficult to

If patients find it difficult to acknowledge all of their symptoms or limitations due to denial, their healthcare may be affected.

acknowledge all of their symptoms or limitations due to denial, their healthcare may be affected. Laurie describes this type of denial in her book as "that niggling worry that so many chronically ill patients have experienced — we don't want to come off as whiny or intractable. In our sickest moments, we need medicine far more than it needs us, and challenging that institution when we're most vulnerable can be extremely difficult."

While denial may be a tough habit to break, it can be done. Patients must

A New Model for Chronic Care

Improving Chronic Illness Care (ICIC), an organization funded by the Robert Wood Johnson Foundation, has developed a chronic-care model with the goal of improving how chronic illness is treated in the United States and worldwide. It has outlined six major goals: improving safety, efficacy and efficiency, and making care more patient-centered, more timely and more equitable.

One intriguing part of the chronic-care model is that it integrates (and encourages) self-management as one important component within a larger model that also urges supportive changes at the level of the community and of health delivery. While change at all these levels is critical, self-management is of particular import, as self-image will greatly affect capability for successful self-management.

learn to value themselves. Self-care is something to feel good about, along with setting realistic goals to avoid

need to let friends and loved ones give support. It is likely that these people are much more understanding and tolerant of their symptoms and limitations than they might think. Another avenue of support includes professional counseling.

Ultimately, what's important to remember is that for patients dealing with chronic conditions, a healthy self-image is possible. Just ask Kristen: "I know in my heart I'm doing everything I can possibly do to lead the best life I can with a chronic illness. It's all a mind-set. You either sink or swim. I choose to swim nearly every day regardless of how difficult it may be." ■



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Medical Information in a Flash

By Ronale Tucker Rhodes, MS



Doctors asking for medical histories from their patients are often met with blank stares. The problem is that many patients don't keep medical records, and if they do, they don't carry the records with them. But current technology could make it much easier to log and store medical data. USB flash drives are all the rage right now, and they are becoming increasingly available and affordable as more and more manufacturers introduce them to market, providing ready access to medical histories whenever and wherever they are needed.

Size Matters

Frequent travelers, athletes, as well as individuals with chronic conditions, often wear medical ID bracelets or tags that attach to clothing in case of emergency. But while those items are convenient because of their size, they don't provide much more information than a name, address, emergency contact and phone number.

Flash drives, on the other hand, ranging in size from a dog tag to a credit card, bracelet, necklace or one- to two-inch handheld device that can be placed in a pocket, can store between 64 megabytes (Mb) and 1 gigabyte (G) of information.

Information Overload

These small devices are computers; they allow for the storage of thousands of items, including data and images. Examples of the types of items that can be input include contact information, doctor visits, medical conditions, medications, allergies, living wills, donor cards, lab tests, X-rays, EKGs, MRIs, CT scans and insurance information.

Privacy Protection

Key to these devices is making them friendly for both the individuals whose information is being stored and for medical personnel whose access can be restricted to

“need to know.” In an emergency, all devices can be plugged into a USB device so that emergency personnel can view critical medical information needed to care for the individual. More personal information can only be accessed by entering a password.

Shop for Selection

A search online will turn up a variety of USB medical flash drives. Keep in mind that the differences in product features vary greatly. Some use only text-based programs

that can be viewed on any computer without the need for special programs. Others have specialized software installed, and yet others will require a membership. Price is usually an indication of the technological capabilities of the device, but it will not alert you to additional costs. Be sure to shop wisely by reading all of the fine print. If specialized software is included, find out if upgrades are available free or for a fee. And, if membership is required, be sure to find out whether an annual subscription fee is charged. ■

Directory of Medical Flash Drives



A Special Connection

The emergency medical record (EMR) flash drive comes in the style of a bracelet, credit card, keychain or necklace. The credit card drive is water-

resistant and allows for 1G of storage. The bracelet comes in leather with 1G of storage, or silicone in three different styles with 256Mb of storage. Necklaces come in three styles — dog tag, firefly and star of life — and offer 1G of storage. The keychain also comes in three styles — firefly, sportster and star of life — and contains 1G of storage. All are ready to be plugged into any USB port.

www.aspecialco.com

drive. Pre-loaded forms make it simple to set up and update medical information. It has 1G of storage, is password-protected and is compatible with Windows Vista/XP and Mac OS.

www.americanmedical-id.com



Chart Scout

The Chart Scout USB Data Drive is pre-loaded with various medical

information database formats that can be filled with personal medical information. The two-inch USB data drive is physician-designed, and information can only be accessed with a personally chosen password. The USB drive can be clipped to a lanyard or to a keychain for accessibility. Data can be accessed from any computer that runs Windows platform, though Win98 and older platforms are not supported without drivers. Three sizes of the Chart Scout USB data drive are available: 256Mb, 128Mb or 64Mb. There are no membership fees and an online customer help desk system is available at chartscout.com. A separate docking cradle is available to charge the device and access data.

www.customusb.com/medical.html



American Medical ID

The e•MedTag Swivel Medical USB is a portable personal health file contained on a compact, easy-to-carry USB thumb



Essential Medical

The Medical Passport is software on a USB flash drive.

Three medical software programs are available — adult, children and pet — each of which uses 20Mb of the 128Mb drive. Software displays critical safety information to guide emergency medical care, but private and more detailed medical information can only be viewed with a password. The software is compatible with any Windows-based computer.

www.ess-med.com



MedicTag

The MedicTag is a digital USB personal medical alert

and information device that combines emergency information with today's technology. A digital memory chip is used to store information on the easy-to-use medical history and alert form, and the distinctive styling and logo will alert medic personnel to special needs and existing medical information. Windows XP/Vista is recommended and will automatically recognize the device; however, it also works with Windows NT/2000.

www.medictag.com



Info Vivo

The Rescue Me USB key uses LifeSaver software emergency medical record software. Once medical information is

entered, paramedics, EMTs, doctors and other medical staff can access the records in a grouped, chronological format.

www.infovivo.com



Medistick

Medistick is a small secure electronic device for storing and accessing personal health records. The device is multilingual, and the software

contains a password-protected area for storing more sensitive data. The records of up to five people can be stored.

www.medistick.ch



MedFlash

MedFlash is a HIPAA-compliant personal health record with 1G of storage, and medical information can be accessed on any Windows-

based computer with a USB port. The device is portable and can be attached to a keychain or necklace. It comes with a user-friendly program that will allow you to quickly enter your information into the emergency data file. Purchase of the MedFlash drive includes one year of the annual membership fee. Program updates are free to registered users.

www.med-flash.com



U Tag

U Tag is a memory stick that looks like a dog tag, and can be worn or attached like a fob to a keychain. The aluminum case sports the medical

snake entwined on a staff and the word ICE (In Case of Emergency). It is password-protected and will work on all national health systems and all versions of Windows. Only the holder of the U Tag can enter or edit details (which are brief — simply name, two contacts, general practitioner, insurance policy number, details of medical conditions and what medications are being taken). Clicking on a flag offers translations into the six main European languages, and holders can store scanned copies of a passport, driver's license and travel insurance in a hidden folder only owners can access.

www.digitaldogtag.co.ukadministrationsets.htm

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.needpsi.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/Itp/ITP_Whats.html
- Platelet Disorder Support Association: www.pdsa.org

Kawasaki Disease

Websites

- American Heart Association (how the disease affects the heart): www.americanheart.org/presenter.jhtml?identifier=4634

- Kawasaki Disease Foundation: www.kdfoundation.org
- KidsHealth: <http://kidshealth.org/parent/medical/heart/kawasaki.html>

Mitochondrial Disease

Websites

- United Mitochondrial Disease Foundation: www.umdf.org

Multifocal Motor Neuropathy (MMN)

Websites

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

Multiple Sclerosis (MS)

Websites

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

Online Peer Support

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

Myasthenia Gravis (MG)

Websites and Chat Rooms

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

Online Peer Support

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

Myositis

Websites



The mission of The Myositis Association, www.myositis.org, is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. (202) 887-0088

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

Online Peer Support

- Juvenile Myositis Family Support Network: www.curejm.com/family_support/index.htm
- Myositis Association Community Forum: www.myositis.org
- Myositis Support Group: www.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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