Palliative Care
Support for the Chronically Ill

Home IVIG Therapy and Improved Quality of Life

Exercise Strategies for Fibromyalgia and CFS

Patient Employment Rights Under the ADA
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IG Living magazine brings together patients, advocates and caregivers in the immune globulin (IG) community.

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Taking Charge of Chronic Illness

COUNTELESS STUDIES have shown that how successful patients are at controlling their disease depends in large part on their level of involvement and responsibility. Of course, it’s important that patients look to their healthcare team to determine the best course of treatment. But, because patients’ day-to-day decisions have a great impact on their quality of life, they need to be at the center of that team as active and informed participants. In this issue, we offer a number of articles to help patients become actively involved in their healthcare to improve their outcomes and, thereby, their quality of life.

Quality of life can be influenced by many factors, but getting the support patients need is perhaps at the forefront. In the past decade, palliative care has been embraced by the medical community as a method of relieving suffering and providing support alongside curative drug therapies. Yet, many patients fail to seek out palliative care because they mistakenly associate it with hospice, which focuses on end-of-life care. As our article “Palliative Care for the Chronically Ill” explains, patients diagnosed with illnesses that require lifelong treatment such as primary immunodeficiency disease can benefit from palliative care, a multidisciplinary approach to specialized medical care for serious illnesses. Studies show that not only does palliative care reduce suffering and increase lifespan, but when it’s implemented, cost of care is significantly reduced. And, fortunately, this type of care is covered by most private and public insurance.

Other influencers of improved quality of life include site of care and route of immune globulin (IG) administration. For the ever-growing number of patients receiving IG therapy, it’s been shown that patients benefit greatly with home versus outpatient hospital infusions. In our article “Benefits of Home IVIG Therapy,” the author, a registered nurse who works as a clinical coordinator for chronically ill children, argues that while home infusions remain a challenge for patients, they are a necessary option. She cites many studies that indicate home infusions, when compared to outpatient hospital infusions, not only improve quality of life, but decrease costs for all — providers, insurance companies and patients.

Currently, there are three route-of-administration choices: intravenous, subcutaneous and facilitated subcutaneous. In our article “Immune Globulin Therapies: Comparing Routes of Administration,” we discuss the differences between the three in terms of patient tolerability and patient and physician preference. As noted, all routes offer benefits and drawbacks, so the goal for patients and their physicians is to choose the one that is best suited to the patient and provides optimal treatment and quality of life.

Finally, the right kind of exercise can also improve quality of life, especially for those who suffer from chronic pain and/or fatigue. In fact, according to the National Institutes of Health, “regular exercise is one of the most effective treatments for fibromyalgia.” Physical therapist Matthew Hansen describes in his article “Exercising with Fibromyalgia and Chronic Fatigue Syndrome” how patients can establish a baseline activity level and then build on it to decrease symptoms and improve activities of daily living. While he highlights the special conditions specific to fibromyalgia and CFS, the approaches he discusses can be applied to many diseases that cause pain and fatigue.

As always, I hope you gain insight from the information presented and enjoy this edition of IG Living.
The Healthcare Divide

By Abbie Cornett

HEALTHCARE IN THE United States has become a battlefield. Political parties have drawn their battle lines and entrenched themselves in their ideologies. Sadly, to date, these ideologies have not addressed many of the issues overwhelming patients and their families — mainly the rising cost of medical care.

While the number of uninsured has steadily declined due to the Affordable Care Act (ACA), many still are unable to pay their medical debt due primarily to two factors. The first is that healthcare in the United States is the most expensive in the world. Compared with other countries, the U.S. spends the most per person on healthcare, and that amount has steadily increased. In 2010, the average cost of healthcare per capita was $8,233. In 2015, that amount increased to more than $10,000. While this growth rate has been fairly low at about 3 percent a year, Kaiser Health System projects it to increase to 4.9 percent a year on a per-capita basis through 2024. If that projection is correct, per person spending on healthcare will reach $15,618.

The second factor is that the burden of payment is being shifted increasingly to the patient through increases in out-of-pocket expenses. Health plans often require hundreds or thousands of dollars in out-of-pocket payments. In a recent poll conducted by The New York Times and the Kaiser Family Foundation, roughly 20 percent of people under age 65 with health insurance reported having problems paying their medical bills in 2015. And, those who are sick or who are prescribed more drugs are much more likely to report problems paying for medication.

Unfortunately, this is where the policymakers and patient population diverge. While the policymakers have been concentrating on access to insurance, the public’s priority remains the high cost of medical care, particularly the rapidly increasing cost of medications.

With the price of drugs increasing at a much faster rate than the relatively flat wages, and an upsurge in out-of-pocket expenses, many people feel that the cost of drugs is the main barrier to care. In 2014 alone, prescription spending increased by a staggering 11.4 percent — an almost 2 percent rise over the projected amount. And, while much of this increase was due to spending on specialty drugs, it reflected an overall growth in spending. According to the Kaiser Health Tracking Poll conducted in April 2015, 76 percent of the public blame drug companies for high drug prices; just 10 percent blame insurers.

The question now is how the federal government will deal with these issues in the upcoming months. As patient advocate for IG Living magazine, I will closely monitor and keep our readers updated on any changes in policy that may affect patients and their families.

ABBIE CORNETT is the patient advocate for IG Living magazine. She can be reached at patient advocate@igliving.com or (800) 843-7477 x1366.

Sources
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**Abbie**» I spoke with a physician who said that liver issues are not uncommon in patients with CVID. The causes — ethyl alcohol, medications, viral illness, autoimmune hepatitis, etc. — are typically the same as in the general population. There is probably a slightly higher incidence of elevated enzymes in those who have autoimmune issues, so this should be tested for. In addition, viral causes with intravenous immune globulin (IVIG) can be a concern, although IVIG has been extremely safe over the last decade. However, we are not aware of any research suggesting the causes of elevated enzymes are different for PI than for anyone else.

**Question » Can CVID cause elevated liver enzymes in children?**

My son has common variable immunodeficiency (CVID). Recently, he was diagnosed with nonalcoholic steatohepatitis, and he has had elevated liver enzymes for several years. Has there been any research conducted concerning liver issues in children with an immune deficiency?

**Abbie**» IVIG dosing for neurologic-associated disorders is generally 2 g/kg, which may be divided over two to four days depending on many issues, including tolerability. It can be infused once or twice depending on the condition, or in some cases, it is continued monthly. Some patients with immune deficiencies who have infections present when being treated with IVIG experience muscle cramps. However, in patients with MMN, cramping may be caused by too low of a dose of IVIG, or by too long of an infusion interval (for instance, receiving 1.5 g/kg every three weeks rather than 1 g/kg every two weeks). A physician can discuss the symptoms with the prescribing neurologist to determine whether treatment needs escalation.

**Question » Can IVIG cause muscle cramping in MMN patients?**

I have multifocal motor neuropathy (MMN), and I have been receiving 85 mg (down to 75 mg) of intravenous immune globulin (IVIG) every three weeks since 2008. In the past, I’ve occasionally had a slight headache. But, recently, right after receiving my infusions, I have severe muscle spasms/cramps, especially in my legs, that can go on for hours. A slight movement in bed can cause these painful cramps. I’m weaker on my right side and have the same experience in my right arm when raising it up to curl my hair, put on makeup, etc. Other times, out of nowhere, the spasms in my legs make it impossible to stand up and walk. Then it passes.

> Have a question? Email us at editor@IGLiving.com. Your information will remain confidential unless permission is given.

ABBIE CORNETT is the patient advocate for IG Living magazine.

By Terry O. Harville, MD, PhD

IN THE PREVIOUS issue, we began a discussion of how the timing disruption of developmental events during the first trimester of pregnancy result in the features of DiGeorge syndrome (DGS). The characteristic “elfin” face with wide-set eyes, small chin and pointed ears is one consequence of this. Additionally, three major medical issues are caused by the timing disturbance: 1) hypocalcem ia (low calcium levels in the blood) due to malformation of the parathyroid glands, 2) cardiac disease due to malformation of the heart and 3) immunodeficiency due to malformation of the thymus.

Hypocalcem ia results from the lack of parathyroid hormone regulation of calcium metabolism. When calcium levels are low, muscles and the metabolic processes in the body don’t work well. Symptoms may include poor eating, lethargy, irritability, muscle twitches and seizures. Hypocalcem ia is not usually noted at birth, but tends to become recognized one to two weeks after birth (usually around day nine), although some of the symptoms may have been developing earlier. Due to when the timing disruption of the parathyroid development occurs, more severe cardiac disease may be present, but interestingly, there may be sufficient thymus development to ultimately provide normal immunity. Therefore, hypocalcem ia does not necessarily indicate that poor immune function may be present in DGS. Indeed, the immunologically worse patients I have dealt with did not have significant calcium problems or severe cardiac malformation.

Disruption of normal heart development is the second of the medically severe issues in DGS. Initially, a series of arching blood vessels are present in what will become the chest of the developing embryo. Centrally, the major blood vessel will begin to enlarge and fold back on itself, and in doing so, the atria and ventricles of heart will begin to take shape. Within this blood vessel, parts of the wall grow inward to meet in the middle to form the two atria and two ventricles, dividing the heart into four chambers. This also separates the right and left parts of the heart into the circulations for the lungs and for the rest of the body, respectively. Additionally, during the folding and central wall formation, the valves of the heart form, as well as placement of the coronary arteries. The blood vessel arches in the chest will either persist or regress to form the major blood vessels from the heart to the lungs, arms, head and the rest of the body.

Thus, when and how long the timing is off determines the extent of cardiac malformation. An earlier disruption of timing (for example, beginning at about four weeks of gestation and perhaps extending for an additional four weeks) may result in essentially nonformation of the heart or very severe cardiac malformations. The heart may not divide into the appropriate chambers, so that a truncus arteriosus, transposition of the great arteries, double-outlet right ventricle or hypoplastic left heart syndrome may occur. Additionally, coarctation of the aorta and interrupted aortic arch (IAA) may develop when the blood vessel arches in the chest fail to form and connect properly. IAA was previously the most common cardiac anomaly associated with having the facial features and hypocalcem ia of DGS, but not necessarily with immunodeficiency. The earlier, more severe cardiac malformations were previously more difficult to manage after birth with high mortality levels. But during the last couple of decades, better neonatal management, better surgical procedures and the use of the medication prostaglandin E1 have allowed for increased survival.

Interestingly, despite the severity of heart malformation due to the early timing disruption, as well as the risk for hypocalcem ia, sufficient thymus development may still occur to prevent severe immune abnormalities. Timing interruptions occurring somewhat later may result in conditions such as tetralogy of Fallot, ventricular septal defect (VSD) or atrial septal defect (ASD). Depending on timing factors, hypocalcem ia and/or underdevelopment of the thymus may also be present, and as a result, immune problems may occur. When the timing is off during a later period in the first trimester, it may result in only a persistent patent ductus arteriosus (PDA) after birth as evidence of cardiac involvement. Even so, some of the patients with the worst immunodeficiency have presented with minimal cardiac issues such as a PDA or clinically insignificant VSD or ASD, and no problems with calcium. Therefore, the severity of immunodeficiency in DGS cannot be predicted by the severity of hypocalcem ia and/or severity of cardiac disease.

We will continue next issue describing what further steps and events should normally occur during fetal development, but — when their timing is off — result in other features of DGS.

TERRY O. HARVILLE, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences and a consultant for immunodeficiencies, autoimmunities and transplantation.
Immune Globulin Therapies: 
Comparing Routes of Administration

By Michelle Greer, RN

IMMUNE GLOBULIN (IG) administration has evolved tremendously since its inception, resulting in several options for patients requiring treatment for primary immune deficiency diseases (PIDs) and autoimmune and neurological disorders. Currently, these options include intravenous IG (IVIG), subcutaneous IG (SCIG) and the latest advancement, facilitated SCIG (fSCIG). Each route of administration is effective in treating various conditions, and neither is superior to another. However, route selection is based on patient tolerability and patient/physician preference (Table 1).

When selecting the route of administration, patients should begin by discussing the options with their prescribing physician. Some questions to answer are: Where does the patient want to receive therapy (home or a clinical center)? Does the patient have difficulty with venous access? Does the patient want to self-administer the therapy?

Another consideration is the patient’s condition. Currently, SCIG and fSCIG are approved by the U.S. Food and Drug Administration (FDA) to treat only PIs; however, off-label use is very common. In addition, each health plan has different criteria for approving IVIG, SCIG and fSCIG. For example, some payers stipulate that in order to cover SCIG, intolerance of IVIG must be demonstrated. Patients are advised, then, to verify health plan requirements to determine coverage.

IVIG

IVIG has evolved in many ways over the last 20 years. At one time, IVIG products were lyophilized (powdered) solutions requiring the extra steps of reconstituting with a diluent and transferring to a bag for administration. Today, however, the majority of currently available IVIG products are liquid solutions that are packaged in various sizes and can be administered directly from their vials, which saves time, expense and the risk of contamination and/or waste. Also, years ago, the available IG brands were stabilized with sugars making infusions for patients with certain comorbidities such as diabetes somewhat complicated. Today, many IG products utilize other stabilizers such as amino acids. Product concentration has also changed. There are now more 10% solutions, which provide more IG protein in less volume. A 5% IVIG solution is adequate for many patients, and for certain patients, the additional fluids will assist with alleviating side effects. But the option of a 10% solution may be preferable for patients who have conditions such as cardiac or renal disease that may be worsened by the additional fluid volume.

IVIG is typically administered monthly, which may be preferable for patients who would rather not infuse more frequently with SCIG. IVIG is administered directly into a vein, and its effects are often immediate, making it the only option for some conditions. This is often true for autoimmune and neurological conditions that require a higher volume (high-dose) of the drug, which means infusions can take from one day to up to five days. (While subcutaneous administration can be challenging for conditions treated with high-dose IG, it is currently prescribed and being studied in clinical trials for several neurological conditions.)

Some patients may tolerate certain brands of IVIG better than others due to their different characteristics. When a product is not tolerated, causing adverse side effects, a change in brand may sometimes be helpful.

Since IVIG requires venous access, IV administration may be difficult to maintain over time, so subcutaneous administration might be considered. If SCIG is not a viable option, a central line might be ordered by the physician in order to continue therapy; however, it should be noted that indwelling catheters or ports include some risk of infection or blood clots.

SCIG

SCIG is administered into the subcutaneous tissue, so venous access is not required. SCIG is also self-administered. The first SCIG product, Vivaglobin (a 16% solution), received FDA approval in 2006. Since then, there have been several changes in brands and their characteristics. Vivaglobin 16% was eventually removed from the market and replaced with Hizentra, a 20% solution. Other 10% solutions that were already approved for IV administration received FDA approval to also be administered subcutaneously. With 10% brands, the volume to be infused is greater than with a 20% solution. However, in some patients, 10% products are better tolerated, so product choice must be individualized.

Number of sites and dosing can also be individualized. The majority of SCIG infusions are weekly, but depending on dosage and patient preference, patients can infuse from between daily and twice a month. More frequent dosing is accom-
accomplished by infusing smaller volumes more often with shorter infusion times and fewer subcutaneous access sites. Calculation of the SCIG dose depends on the brand and the prescribing physician, although FDA does recommend a conversion rate, which is typically calculated at 137 percent of the IVIG dose. Despite this recommendation, some physicians simply convert the IVIG to SCIG dose at 100 percent and adjust it as necessary. Factors to consider when dosing include how low IgG levels are in PI patients, the total volume to be infused and the clinical response to treatment.

fSCIG

Currently, the only FDA-approved fSCIG product is HYQVIA, which is administered monthly versus more frequently as with other SCIG products, meaning larger volumes of the drug are administered at one time. With HYQVIA, a medication called hyaluronidase is given prior to the infusion to modify the subcutaneous space to accommodate the additional fluid. Hyaluronidase is an enzyme that temporarily breaks up hyaluronan in the subcutaneous space and is administered as a subcutaneous push. Ten minutes after hyaluronidase is administered, IG is administered in one or two sites subcutaneously. The fluid dose takes approximately 24 hours to 48 hours to be absorbed. So, even if there is no irritation at the injection site, there is local swelling that results from the large amount of fluid infused. When initiating fSCIG, there is a ramp-up phase so patients can get used to infusing the large volumes administered for the total monthly dose.

Monthly dosing intervals combined with self-administration are a benefit of fSCIG. Another benefit is that if patients do not desire self-administration, fSCIG can be infused by a healthcare practitioner in any site of care. If fSCIG is to be administered at home by a healthcare practitioner indefinitely, insurance approval would need to be obtained for coverage.

SCIG versus IVIG Dosing

With SCIG, more frequent dosing results in a more consistent IgG level on an ongoing basis. With IVIG, IgG levels peak immediately after the infusion and steadily decline until the next infusion. To date, no study has demonstrated that the pattern of IgG levels seen with either IVIG or SCIG dosing is more effective in treating PIs or any other condition.

Three Routes, Three Options

The routes of administration available today offer patients three different options to benefit from IG therapy. Of course, each has its benefits and drawbacks. Therefore, it is important for patients and their prescribing physician to evaluate which route is best suited to each patient’s lifestyle, tolerability and efficacy for the condition treated.

Michelle Greer, RN, is senior vice president of sales for NuFACTOR Specialty Pharmacy.

<p>| Table 1. Considerations for Selecting Route of IG Administration |
|----------------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|</p>
<table>
<thead>
<tr>
<th>Route of Administration</th>
<th>Site of Administration</th>
<th>Venous Access</th>
<th>Patient Self-Administration</th>
<th>Systemic Side Effects</th>
<th>Site Reactions</th>
<th>Additional Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>IVIG</td>
<td>Hospital outpatient infusion center; physician office; home</td>
<td>Yes</td>
<td>Very rare; requires MD approval</td>
<td>Higher potential than SCIG and fSCIG</td>
<td>Rare at site of IV</td>
<td>Pre-meds routinely ordered</td>
</tr>
<tr>
<td>SCIG</td>
<td>Predominantly at home</td>
<td>No</td>
<td>Almost always</td>
<td>Lower potential than IVIG</td>
<td>Common at infusion site</td>
<td>Pre-meds at discretion of MD; less routine due to decreased potential for systemic reactions</td>
</tr>
<tr>
<td>fSCIG</td>
<td>Mostly at home; some at physician office; rarely in hospital outpatient infusion center</td>
<td>No</td>
<td>Up to prescribing MD and patient</td>
<td>Lower potential than IVIG</td>
<td>Common at infusion site</td>
<td>Pre-meds at discretion of MD; less routine due to decreased potential for systemic reactions; requires additional subcutaneous injection of hyaluronidase prior to SCIG</td>
</tr>
</tbody>
</table>
Research

NAF Conducts First International MMN Patient Survey

The Neuropathy Action Foundation (NAF) invites all multifocal motor neuropathy (MMN) patients to participate in the first International MMN Patient Quality of Life Survey. The survey’s goal is to examine the quality of life (QOL) of MMN patients to increase awareness among researchers, providers, the general public and public policy officials that MMN is a serious, yet treatable condition when diagnosed quickly and accurately.

Participation in the survey, which is anonymous and can be taken only once, takes approximately 15 to 20 minutes to complete. The NAF is happy to compensate individuals $50 for completing and submitting the survey. If compensation is requested, individuals must answer the last section of the survey that will collect the necessary contact information for payment. If individuals would prefer to waive compensation and allow the NAF to keep the money for other projects, that section can remain blank to remain anonymous.

To participate in the survey, go to www.surveymonkey.com/r/MMNPatientSurvey. For additional information or questions, visit the NAF website at www.neuropathyaction.org, or call (877) 512-7262. The NAF hopes that the results of this survey will lead to better care and treatments for MMN patients.

Medicines

FDA Accepts Biologics License Application for New IVIG Product

Green Cross Corp.’s biologics license application for IVIG-SN (human normal immunoglobulin G for intravenous administration) for the treatment of primary immunodeficiency disease (PI) has been accepted by the U.S. Food and Drug Administration. The approval comes after IVIG-SN demonstrated positive results in a Phase III study in patients with PI that met its primary endpoint of no acute serious bacterial infections. “The expected introduction of IVIG-SN will provide a meaningful immune globulin product option for clinicians and their patients that further builds on the success already achieved with our products in other parts of the world,” said EC Huh, PhD, president of Green Cross Corp. “IVIG-SN marks a major step toward our ultimate goal of expanding biologics business to the U.S. marketplace.”

Conferences

10th Annual Neuropathy Action Foundation Awareness Day Is June 23

The Neuropathy Action Foundation (NAF) is hosting its 10th Annual Neuropathy Action Awareness Day from 9:30 a.m. to 4:00 p.m. on June 23rd at the Intercontinental Hotel in Los Angeles. The event is an opportunity for patients to interact with other patients, providers and exhibitors, as well as to learn about neuropathy and how to cope with it and get updates on policy issues and patient advocacy. Highlights include educational sessions, an exhibit area, a sit-down luncheon and a silent auction. Individuals who are unable to attend the event in person can participate via video livestreaming technology free of charge. A computer and Internet access are required, and individuals will be able to ask speakers questions and receive answers in real time. The day will also be recorded so it can be watched on the NAF website after the event has ended.
New Report Discusses Medicare Enrollment and Drug Appeals

“Medicare Trends and Recommendations: An Analysis of 2014 Call Data from the Medicare Rights Center’s National Helpline” is a new report that includes an in-depth discussion of two important issues heard on the Medicare Rights’ Helpline: 1) navigating Medicare Part B enrollment and 2) navigating Part D prescription drug appeals. Of the 17,000 questions posed by older adults and people with disabilities, their family members and healthcare professionals on the helpline in 2014, these two issues were among the most-asked questions.

According to the report, many individuals who call Medicare Rights are confused by Medicare enrollment rules and, specifically, whether to take or decline Medicare Part B, which covers doctor and other services. In addition, many frequently don’t understand why their prescription drug is denied, and they are confused by the Part D appeals process, including whether their appeal has been filed, what level of appeal they are at and what their doctors may have done on their behalf.

The report includes a comprehensive set of policy recommendations intended to improve access to affordable healthcare. Among the recommendations regarding these issues are better education for newly eligible beneficiaries and employers; how to streamline and align enrollment periods; and recommendations to include the reason for a drug denial in the pharmacy counter notice and allow an immediate request for an appeal. The report can be accessed at www.medicarerights.org/2014-medicare-trends.
More free time to live my life my way.

HYQVIA, the only once-a-month subQ Ig*1
For adults with primary immunodeficiency

Schedule an appointment with your physician to see if HYQVIA is right for you.

* subQ Ig, also known as subcutaneous immune globulin.

Reference

Please see the Detailed Important Risk Information on the adjacent pages and the Brief Summary of HYQVIA Prescribing Information, including Boxed Warning, on the reverse side.

To learn more about HYQVIA, visit www.HYQVIA.com
**INDICATION AND USAGE**

HYQVIA (Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase) is an immune globulin with a recombinant human hyaluronidase indicated for the treatment of Primary Immunodeficiency (PI) in adults. This includes, but is not limited to, common variable immunodeficiency (CVID), X-linked agammaglobulinemia, congenital agammaglobulinemia, Wiskott-Aldrich syndrome, and severe combined immunodeficiencies.

Limitation of Use: Safety and efficacy of chronic use of recombinant human hyaluronidase in HYQVIA have not been established in conditions other than PI.

**Detailed Important Risk Information**

HYQVIA can cause serious side effects. Call your healthcare professional if you get:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of swelling in your brain.
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s). These could be signs of a blood clot.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.
- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a lung problem.

These are not all the possible side effects with HYQVIA. Talk to your healthcare professional about any side effects that bother you or that don’t go away.

**What is the most important information that I should know about HYQVIA?**

- HYQVIA can cause blood clots.
- Call your healthcare professional if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your healthcare professional may perform blood tests regularly to check your IgG level.
- With your consent, your healthcare professional may provide blood samples to Baxalta Healthcare Corporation to test for antibodies that may form against the hyaluronidase part of HYQVIA.
- Do not infuse HYQVIA into or around an infected or red swollen area because it can cause infection to spread.
- Talk to your healthcare professional if you become pregnant. Women who become pregnant during HYQVIA treatment are encouraged to enroll in the HYQVIA Pregnancy Registry by calling Medical Information at 1-866-424-6724.
You may be eligible to save up to $4,000 on HYQVIA

If you are starting or currently receiving treatment with HYQVIA (Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase) for PI, you may be eligible to save up to $4,000 on your deductible/co-payment/co-insurance costs over 12 months.

To enroll, call us.
We’ll take care of the rest.

Terms and Conditions
- To be eligible, patients must: 1) be starting or receiving treatment with (and have a current prescription for) HYQVIA with an ICD9 or ICD10, as applicable, for adult (≥18 years of age) Primary Immunodeficiency (PI); and 2) have commercial insurance that covers medication costs for HYQVIA treatment and allows for co-pay/coupon assistance.
- This manufacturer coupon program is not valid for prescriptions reimbursed, in whole or in part, by Medicaid, Medicare, Medicaid, VA, DoD, TRICARE, or any other federal or state healthcare programs, including state pharmaceutical assistance programs, and where prohibited by the health insurance provider or by law.
- The coupon program provides a maximum benefit of $4,000 for eligible out-of-pocket costs and expires 12 months from date of activation. Eligible costs include deductible, co-payment, and co-insurance costs for HYQVIA. Non-medications expenses, such as ancillary supplies or administration-related costs, are not eligible.
- Patients are eligible for a maximum benefit of $4,000 in total Baxalta support in any 12-month period, including any amount received as part of the GAMMA GALDAR LIQUID SubQ CoPay Program.
- Acceptance of this offer must be consistent with the terms of benefits provided by patient’s health insurance provider.
- Offer limited to one card per person and expires 12 months from date of activation and may not be combined with any other coupon, discount, prescription savings card, rebate, free trial or other offer.
- This program is only valid for residents of the United States, excluding Puerto Rico and other U.S. territories.

Baxalta reserves the right to change or discontinue this program at any time without notice.
This is not health insurance.

Patient Instructions
By using this coupon, you are certifying that:
1) You meet the eligibility criteria and have read and agree to the terms and conditions of this program;
2) You will not, at any time, submit any costs for the product dispensed pursuant to this coupon to any government program for reimbursement;
3) You are permitting your personal information, including name, address, phone number, email address, and information related to health insurance and treatment, to be shared with Baxalta and companies working with Baxalta for the purpose of administering this program;
4) You will notify your health insurance provider or other third-party payer of the use of this program if required to do so; and
5) If your insurance situation changes it is your responsibility to notify Baxalta immediately by contacting the MyIgSource Patient Support Program.

For questions about this program, patients and caregivers can call the MyIgSource Patient Support Program at (855) 250-5111.
For pharmacy instructions please visit www.HYQVIA.com

What are the possible or reasonably likely side effects of HYQVIA?

After HYQVIA infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused. Mild or moderate pain, redness, swelling, or itching may occur at the site of infusion and generally go away in a few hours.

Local reactions are less likely after the first few infusions. The most common side effects of HYQVIA are headache, fatigue, nausea, fever, and vomiting. Antibodies to the hyaluronidase component of HYQVIA were formed in some patients taking HYQVIA. It is not known if there is any long-term effect. In theory, these antibodies could react with your body’s own PH20. PH20 is present in the male reproductive tract. So far, these antibodies have not been associated with increased or new side effects.

What is HYQVIA?

HYQVIA is a liquid medicine containing immune globulin and recombinant human hyaluronidase. HYQVIA contains IgG antibodies, collected from human plasma donated by healthy people. The antibodies help your body to fight off bacterial and viral infections. The hyaluronidase part of HYQVIA helps more of the immune globulin get absorbed into the body to fight infection.

Before starting HYQVIA, tell your healthcare professional if you have or had any kidney, liver, or heart problems, a history of blood clots, because HYQVIA can make these problems worse. Also tell your doctor if you have IgA deficiency or a history of severe allergic reactions to immune globulin (IgG) or other blood products, or are pregnant, trying to become pregnant or are breast feeding.

How should I take HYQVIA?

HYQVIA is infused under the skin (subcutaneously) up to once every 4 weeks. You can get HYQVIA at your healthcare professional’s office, clinic, or hospital. You can use HYQVIA at home. You and your healthcare professional will decide if home self-infusion is right for you. Do not use HYQVIA at home until you get instructions and training from your healthcare professional.

Who should not take HYQVIA?

Do not take HYQVIA if you are allergic to IgG, hyaluronidase, or other blood products, or have IgA deficiency with antibodies to IgA.

To report suspected side effects, contact Baxalta US Inc. at 1-866-888-2472 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Please see Brief Summary of HYQVIA Prescribing Information on following page, including Boxed Warning.
INDICATION AND USAGE
HYQVIA [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] is an immune globulin with a recombinant human hyaluronidase indicated for the treatment of Primary Immunodeficiency (PI) in adults. This includes, but is not limited to, common variable immunodeficiency (CVID), X-linked agammaglobulinemia, congenital agammaglobulinemia, Wiskott-Aldrich syndrome, and severe combined immunodeficiencies.

Limitation of Use:
Safety and efficacy of chronic use of recombinant human hyaluronidase in HYQVIA have not been established in conditions other than PI.

Selected Important Risk Information about HYQVIA
HYQVIA can cause blood clots. Call your healthcare professional or go to your emergency department right away if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body. These could be signs of a blood clot.

Do not use HYQVIA if you are allergic to immune globulin (IgG), hyaluronidase, or other blood products, or have IgA deficiency.

These are not all the possible side effects with HYQVIA. Talk to your healthcare professional about any side effects that bother you or that don’t go away.
Brief Summary of Prescribing Information
HYQVIA [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase]

The following summarizes important information about HYQVIA (pronounced Hi-Q-via). Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare professional. If you have any questions after reading this, ask your healthcare professional.

What is the most important information that I should know about HYQVIA?

- HYQVIA can cause blood clots.
- Call your healthcare professional if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your healthcare professional may perform blood tests regularly to check your IgG level.
- With your consent, your healthcare professional may provide blood samples to Baxalta Healthcare Corporation to test for antibodies that may form against the hyaluronidase part of HYQVIA.
- Do not infuse HYQVIA into or around an infected or red swollen area because it can cause infection to spread.
- Talk to your healthcare professional if you become pregnant. Women who become pregnant during HYQVIA treatment are encouraged to enroll in the HYQVIA Pregnancy Registry by calling Medical Information at 1-866-424-6724.

What should I tell my healthcare professional before I start using HYQVIA?

Before starting HYQVIA, tell your healthcare professional if you:

- Have or had any kidney, liver, or heart problems or history of blood clots because HYQVIA can make these problems worse.
- Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products.
- Are pregnant, trying to become pregnant or are breast feeding.

What is HYQVIA?

HYQVIA is a liquid medicine containing immune globulin and recombinant human hyaluronidase. HYQVIA contains IgG antibodies, collected from human plasma donated by healthy people. The antibodies help your body to fight off bacterial and viral infections. The hyaluronidase part of HYQVIA helps more of the immune globulin get absorbed into the body to fight infection.

Who should not take HYQVIA?

- Do not take HYQVIA if you: Are allergic to IgG, hyaluronidase, or other blood products.
- Have IgA deficiency with antibodies to IgA.

How should I take HYQVIA?

- HYQVIA is infused under the skin (subcutaneously) up to once every 4 weeks.
- You can get HYQVIA at your healthcare professional’s office, clinic, or hospital.
- You can use HYQVIA at home. You and your healthcare professional will decide if home self-infusion is right for you.

What are the possible or reasonably likely side effects of HYQVIA?

After HYQVIA infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused.

The following local reactions may occur at the site of infusion and generally go away in a few hours. Local reactions are less likely after the first few infusions: mild or moderate pain, redness, swelling, and itching.

The most common side effects of HYQVIA are headache, fatigue, nausea, fever, and vomiting.

Antibodies to the hyaluronidase component of HYQVIA were formed in some patients taking HYQVIA. It is not known if there is any long term effect. In theory, these antibodies could react with your body’s own PH20. PH20 is present in the male reproductive tract. So far, these antibodies have not been associated with increased or new side-effects.

Call your healthcare professional or go to your emergency department right away if you get:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of swelling in your brain.
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s). These could be signs of a blood clot.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.
- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a lung problem.

These are not all of the possible side effects for HYQVIA. For more information about HYQVIA, go to www.HYQVIA.com. For more information on patient resources and education, please visit www.immunedisease.com.
Resolution

IDF’s Medical Advisory Committee Issues Resolution on Diagnostic Vaccine Challenge

In response to a recent arbitrary requirement by some insurers requiring a diagnostic vaccine challenge for all previously diagnosed individuals with common variable immunodeficiency (CVID), the Medical Advisory Committee of the Immune Deficiency Foundation (IDF) has issued a landmark resolution explaining the danger posed by the requirement. According to the committee, the requirement is not consistent with the standard of care for people with CVID, causing extreme concern and prompting the resolution.

“We are especially troubled by a recent trend among some health insurers to require patients with an established diagnosis of antibody deficiency to present evidence that they have failed to produce antibody after vaccine challenge, even if their diagnosis was established years earlier,” the resolution states. “IDF supports this vaccine challenge requirement for newly diagnosed patients with IgG levels greater than 200 mg/dl, but not for individuals already receiving immune globulin (IG) replacement therapy. This is because without this evidence, approval for continued IG therapy is denied and patients are forced to stop treatment to perform the required assessment that will take several months.”

According to IDF, many individuals with CVID have been forced to go without their lifesaving IG therapy for five to eight months to meet the vaccine requirement mandated by insurers, risking serious or potentially fatal infection that would normally have been prevented by their IG therapy. “This practice of insurers arbitrarily mandating that all established patients carrying a diagnosis of CVID must risk their health and well-being to submit evidence of vaccine non-responsiveness is both unnecessary and unjustified,” explains Rebecca H. Buckley, MD, chair of the IDF Medical Advisory Committee, J. Buren Sidbury professor of pediatrics and professor of immunology at Duke University Medical Center. “There are occasionally situations where immunologists may find it advisable to stop IG replacement to perform a vaccine challenge, but these decisions must be made by qualified medical professionals acting on behalf of their patients’ best interests, not insurers.”

The complete resolution can be read at primaryimmune.org/wp-content/uploads/2016/01/IDF-Medical-Advisory-Committee-Resolution-01-27-2016.pdf.

Medicines

Kedrion Gains Commercial Rights to Market Bivigam in U.S.

Kedrion Biopharma has been given exclusive rights to market Biotest Pharmaceuticals’ Bivigam (intravenous immune globulin [human] 10% liquid) to treat primary immunodeficiency disease (PI) in the U.S. While Bivigam was approved by the U.S. Food and Drug Administration in 2012, Kedrion relaunched the product in January. In addition to Bivigam, Kedrion owns the rights to market Gammaked (immune globulin injection [human], 10% caprylate/chromatography purified), a sucrose-free immune globulin therapy indicated for the treatment of chronic inflammatory demyelinating polyneuropathy, PI and idiopathic thrombocytopenic purpura.

“The number of people being treated for primary immunodeficiency, or PI, continues to rise year after year, thanks to recent and important advances in the awareness and diagnosis of this rare and serious disorder,” said Paolo Marcucci, president and chief executive officer of Kedrion Biopharma. “We also know that PI tends to affect different individuals in various ways. For this reason, it is important for patients and their caregivers to have multiple treatment options from which to choose.”

Palliative care has evolved as a subspecialty of medicine that helps patients and their families improve quality of life.

By Abbie Cornett
Palliative care is a term often used interchangeably and incorrectly as a word for hospice. Palliative care and hospice care do bear some similarities. They use the same multidisciplinary approach and share the similar goal of making patients more comfortable by looking for ways to alleviate symptoms and manage pain. Both also use a team approach to improve the quality of lives of patients and their families using specially trained doctors, psychologists, nurses, social workers, massage therapists, pharmacists, nutritionists, chaplains and other healthcare professionals.

What is different about hospice and palliative care in the U.S. is the time when patients utilize them. Hospice care is sought when all medical treatments have been exhausted or when patients wish no more extreme measures be taken to extend their lives. The goal of hospice is to ease patients’ suffering with no curative intent. To receive benefits under Medicare for hospice services, a patient’s hospice doctor and his or her regular physician must certify that the patient is terminally ill and has less than six months life-expectancy.

Palliative care, on the other hand, is meant to relieve suffering and provide support in combination with curative treatments. The main goals of palliative care are “symptom management; establishing goals of care that are in keeping with the patient’s values and preferences; consistent and sustained communication between the patient and all those involved in his or her care; psychosocial, spiritual and practical support to both patients and their family caregivers; and coordination across sites of care.”

Palliative care is designed for patients of all ages and their families who have been diagnosed with a chronic or life-threatening illness at any stage of disease. Palliative care patients fall into three categories. The first includes patients who have been diagnosed with a curable disease such as some types of cancers. The second is comprised of patients who have been diagnosed with a chronic illness such as common variable immunodeficiency who will undergo treatment throughout their lives. And, the third is devoted to those who have a progressive illness such as multiple sclerosis.

According to Marcia Penido, LCSW, MPH, ACM, director of care coordination at Huntington Hospital in Pasadena, Calif., “The goal of a hospital’s multidisciplinary team is to maximize the quality of life for both the patients and their loved ones.” At Huntington Hospital, their approach is to 1) relieve pain, symptoms and stress caused by serious illness; 2) provide care in hospital and outpatient clinical settings; and 3) offer consulting after diagnosis of a serious, progressive illness.

**History of Palliative Care**

Palliative care is not new. Its origins go as far back as medieval times when the terms *hospice* (derived from the root word *hospitality*) and *palliative* (derived from the Latin root word *palliare*, to cloak) were used to describe rest for weary travelers. The first modern concept of hospice care can be traced back to work performed in 1948 by Dame Cicely Saunders who created St. Christopher’s Hospice. But, in the past, the practice of medicine focused on curing disease with little discussion about quality of life for patients or their loved ones. In fact, much of the medical community viewed treatments such as morphine with suspicion, fearing the unintended consequence of treatments not meant to be curative.

**Palliative care is designed for patients of all ages and their families who have been diagnosed with a chronic or life-threatening illness at any stage of disease.**

It wasn’t until 2006 that palliative care was recognized as a subspecialty of internal medicine. Today, palliative care is looked at in a much different light, with the medical community embracing the idea of treating the whole patient, not just the illness. This requires taking a whole new look at the patient-physician relationship. When patients enter a palliative care program, they and their families become partners with the palliative care team. The team works together to explore options of treatment and manage any symptoms such as pain that patients may be experiencing. The team’s goal is to improve the lives of patients by reducing their suffering and to offer support for their families.

**Who Should Consider Palliative Care?**

Palliative care should be considered for any patient who has been diagnosed with a life-threatening disease or chronic illness.
In fact, the American Academy of Hospice and Palliative Medicine recommends physicians “don’t delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.”

It is been shown that patients who reduce their stress and suffering alongside standard care live longer.

It should be noted, however, that palliative care for adults and children differs. As the organization Get Palliative Care explains, “Children are not simply little adults.” Because of their unique anatomy and physiology, and because they are growing during the course of their illness, disease doesn’t necessarily progress the same way in a child as it does in an adult. As such, they need care that is individualized to them. The World Health Organization outlines specific principles to follow that are the same for adults but that also take into account the special needs of children and their families.

Palliative care for the chronically ill makes sense for two main reasons. The first is that patients and their families in palliative care programs have a greater quality of life and demonstrate better outcomes. It’s been shown that patients who reduce their stress and suffering alongside standard care live longer. And, it’s been proven that if patients have untreated side effects such as nausea, pain and depression, the chances of them dying from complication increases.

A second reason palliative care makes sense is from a financial perspective. The cost of treating patients who receive palliative care during hospitalization is significantly less. In a 2008 study, researchers found that palliative care patients discharged alive had an adjusted net savings of $1,696 in direct costs per admission and $279 in direct costs per day; palliative care patients who died in the hospital had an adjusted net savings of $4,908 in direct costs per admission and $374 in direct costs per day.

Another study, which analyzed data from 38,475 inpatient stays for people 18 or older hospitalized for seven to 30 days between January 2009 and June 2012, found that “among patients who died in the hospital, there was a significant cost savings from palliative care of $3,426 per inpatient stay.” This was especially true for those who received palliative care within the first 10 days of hospitalization.

Accessing Palliative Care

The number of palliative care programs has grown rapidly in recent years, although it has not kept up with need. According to the National Palliative Care Research Center’s 2015 State-by-State Report Card, an annual report that tracks the growth of hospice palliative care programs across the 50 states and identifies areas where persistent gaps in access remain, “access to palliative care remains inadequate for millions of Americans living with serious illness despite continuing growth in the number of U.S. hospitals reporting palliative care programs.” While, currently, 88 percent of hospitals report they have some type of program in place, one-third of hospitals report no palliative care services of any kind. And, although access to palliative care in community settings (home, nursing home, assisted living) is available in some areas, it is limited for people who are not hospice-eligible (actively dying).

To locate a palliative care program, patients should consult their treating physician for a referral. However, if a physician is unaware of a program, there are three national resources to assist in locating one, including Get Palliative Care (getpalliativecare.org), Palliative Doctors (palliativedoctors.org) and the National Hospice and Palliative Care Organization (www.nhpco.org).

Unlike in the past, most private insurance policies now cover palliative care. The care team, an additional level of support included in a palliative care program, can help patients understand what is covered. In addition, Medicare and Medicaid cover palliative care services in the hospital, in rehabilitation settings and in skilled nursing or hospice facilities. While Medicare and Medicaid don’t use the word “palliative,” the services are the same. However, where patients access palliative care under Medicare is different, and what services are available depends on whether they have Medicare Part A or B. What is covered by Medicaid also differs depending on the program.

Maximizing Quality of Life

Palliative care programs provide patients with a team of healthcare professionals whose goals for care are in accordance with theirs and their families. These programs offer a standard of care for all chronically ill patients to support them and their
families while focusing on symptom relief and comfort. According to studies, patients who receive palliative care “have improved quality of life with less depression and symptom burden; feel more in control; are able to avoid risks associated with treatment and hospitalization; and have decreased costs with improved utilization of healthcare resources.” And, caregivers, family and friends report “greater satisfaction with the quality of care and attention to caregiver needs.”

“The most important outcomes of palliative care are that the patient’s quality of life is maximized and they receive the medically appropriate level of care that they want,” says Huntington’s Penido.

ABBBIE CORNETT is the patient advocate for IG Living magazine.

Resources
Benefits of Home IVIG Therapy

IVIG infusions performed in the home have been associated with increased quality of life and decreased healthcare costs, but reimbursement for this site of care remains a challenge.

By Ashlea E. Cook, RN

**WITH THE INCREASING** use of immune globulin (IG) replacement therapy as long-term therapy for patients with varying diseases, the number of IG units administered yearly in the United States now reaches into the millions. IG replacement therapy is approved by the U.S. Food and Drug Administration (FDA) to treat idiopathic thrombocytopenic purpura, B-cell chronic lymphocytic leukemia, HIV infection, bone marrow transplantation, Kawasaki disease and primary immunodeficiency disease (PI) — with the latter disease state utilizing the greatest amount of the drug. Where IG is administered — in the home versus other sites of care — is essential to patients’ quality of life, as well as to the efficiency and cost-effectiveness of the healthcare system.

**IVIG Treatment**

The introduction of intravenous IG (IVIG) 30 years ago has had a dramatic impact on the health and lives of patients who require long-term IG replacement therapy. With IVIG, increased doses of the drug can be administered (compared with the earlier intramuscular route), allowing patients to achieve normal serum IgG concentrations. Initially, IVIG treatments were administered only in hospitals as a safety precaution. However, as knowledge of the safety profile of IVIG increased, administration moved to outpatient care settings. With safe outpatient track records, increased safety controls and training of homecare nurses established, home IVIG administration was explored in an effort to increase patients’ health and quality of
life. In the home setting, potential adverse side effects of IVIG infusions are handled much the same as they are in the hospital. Skilled home infusion nurses are trained to administer IVIG, assess for signs of anaphylaxis and other adverse effects, and treat appropriately. Anaphylaxis treatment protocols include continued monitoring of vital signs, and adverse effects are treated with the administration of appropriately prescribed medications such as Tylenol and Benadryl.

**Quality of Life Benefits**

The benefits of home IVIG infusions have been brought to the forefront in a number of studies. One study that compared rates of pneumonia and bronchitis in PI patients receiving IVIG therapy in outpatient hospitals versus in the home demonstrated significantly lower rates of infection in patients receiving treatment at home.

Beyond the medical benefits, patients receiving IVIG infusions at home are noted to have increased quality of life due to greater control over day-to-day activities. For instance, home IVIG infusions have eliminated many of the hurdles surrounding scheduling conflicts for patients. And, they have been noted to be especially important in pediatric immunodeficiency care because they increase family functioning and provide greater independence.

The ability to receive treatment in the comfort of one’s home and on one’s own schedule has resulted in improvements in patient treatment satisfaction. It has also been shown that with home IVIG treatment, patients and their families become active participants in their lifelong therapy, leading to greater compliance and improved medical outcomes. On the flip side, frequent trips to the hospital for IG administration can have a detrimental effect on the patient and family’s quality of life, requiring continual interruption of daily activities, frequent absences from school and work, inability to participate in travel and leisure activities, and a general loss of control over their lives. These factors have been noted to lead to a decrease in adherence to the prescribed treatment plan, which in turn has repeatedly shown to lead to increased hospitalizations, physician visits, nursing home admissions and avoidable healthcare costs. In short, home IVIG infusions have generated positive effects on healthcare, leading to improved health outcomes, decreased healthcare expenditures and increased participation of patients in the workforce and society as a whole.

**Cost-Saving Benefits**

It has been shown that both healthcare and pharmaceutical costs are significantly less for home infusions than those administered in outpatient infusion centers. One observational study noted a statistically significant difference in cost (in 2010 dollars) per home IVIG infusion at $1,452, which is 31 percent less than per outpatient infusion. This difference in cost per infusion is an estimated annual savings of between $18,876 and $26,136 for one patient receiving 13 to 18 home infusions per year. Not only are these savings considerable for insurance companies and healthcare providers, patients benefit as well in the form of lower co-pays, co-insurance and out-of-pocket costs.

Costs are further decreased with improved adherence by patients receiving home infusions. As referenced above, deviation from the recommended treatment plan, which is often seen in patients who receive their treatments outside of the home, leads to increased emergency room visits, hospitalizations, physician visits, nursing home admissions and overall higher healthcare costs. In addition, there are indirect costs such as patients’ lost work time and overall decreased societal productivity.

**Healthcare Implications**

The National Home Infusion Association estimates there are approximately 700 to 1,000 home infusion companies in operation, and those numbers continue to increase as the trend of decentralized healthcare expands. The needs of chronically ill patients such as those with PI are gaining more attention both from healthcare providers and healthcare business leaders. Alternative sites of treatment such as home infusions are becoming key solutions to improved clinical and financial management of chronic care patients. However, the convoluted details of insurance coverage are creating headaches for patients and providers who wish to utilize this treatment option, especially those covered under Medicare and Medicaid.

Presently, the Centers for Medicare and Medicaid Services offers coverage for an increasing number of infusion drugs such as
as IVIG, but it fails to cover the required services, equipment and supplies necessary to provide home infusion therapy. Many efforts like the Medicare Home Infusion Therapy Consolidated Coverage Act of 2006 have attempted to shed light on the need for comprehensive coverage of both the drug and services under Medicare Part B; however, they have been unsuccessful to date. (It should be noted that, currently, the Medicare IVIG Access Act is studying the impact of providing payment and items for services needed for in-home IVIG treatment of PI.) As such, many Medicare/Medicaid beneficiaries are unable to benefit from home infusions because they can’t afford expensive out-of-pocket costs. With approximately 30 million Americans enrolled in Medicare/Medicaid10 and approximately 500,000 cases of PI in the United States, this adds up to a great number of missed opportunities for home IVIG infusions.

Patients with private insurance or Advantage Medicaid plans are fortunate to be able to receive comprehensive insurance coverage of in-home IVIG infusions. But those who do not are forced to receive therapy in hospitals or outpatient treatment centers. This imbalance of options keeps providers from prescribing home therapy to their patients about this option. Patients need up-to-date information pertaining to the benefits, safety and adverse effects of both hospital and home IG infusion options. And, the power of insurance companies to overrule what patients and their physicians consider the best site-of-care option due to uncomprehensive insurance coverage needs to be eliminated.

ASHLEA E. COOK, RN, is a clinical coordinator for three divisions at Columbia University Medical Center that care for kids with chronic conditions.

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Presently, the Centers for Medicare and Medicaid Services offers coverage for an increasing number of infusion drugs such as IVIG, but it fails to cover the required services, equipment and supplies necessary to provide home infusion therapy.

Healthcare providers are encouraged to identify patients who are suited to receive home IVIG therapy and educate them and their families about this option. Patients need up-to-date information pertaining to the benefits, safety and adverse effects of both hospital and home IG infusion options. And, the power of insurance companies to overrule what patients and their physicians consider the best site-of-care option due to uncomprehensive insurance coverage needs to be eliminated.

Site-of-Care Option Is a Necessity

The need for IG replacement therapy is a reality for over half a million Americans diagnosed with PI today, and the need is continuing to increase. For PI patients, IG replacement therapy is a lifelong partner in their health and well-being. To maximize the therapy benefits, healthcare providers should ensure that site-of-care options for IG therapy that lead to improved quality of life and well-being are presented to patients and their families.

Home infusions have been shown to improve quality of life, independence and medication adherence for a significant number of PI patients. PI patients receiving home IG infusions are able to be productive members of society with a reduction in the number of hours and days missed in educational and vocational activities. They are also associated with significant financial benefits, including a cost savings of almost 30 percent per infusion, which benefits patients and the healthcare system as a whole.
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Understanding Chronic Granulomatous Disease

Different from other immunodeficiencies, CGD is becoming better understood with improvement in diagnosis and treatment.

By Bob Geng, MD
DR. CHARLES JANEWAY first described chronic granulomatous disease (CGD) in 1954. At the time, immunodeficiency was characterized by recurrent infections due to low immunoglobulin levels. However, Dr. Janeway described several male patients who had recurrent infections and an enlarged liver and spleen, but elevated immunoglobulin levels. Over the next several years, more cases similar to these, along with granuloma formation and severe inflammation, were reported. In the late 1960s, Staphylococcus bacteria was discovered to be the predominant form of infection in CGD patients, and while neutrophils (white blood cells) in CGD patients could ingest these bacteria without difficulty, they could not digest them. Then, from the 1970s through the 1990s, other genetic discoveries of specific defects leading to CGD were made, which greatly improved our understanding of the disease.

What Causes CGD?

CGD results from the inability of cells in the innate immune system (neutrophils and monocytes) to make superoxide compounds that could effectively kill bacteria or fungus that they ingest. Neutrophils are the main cells of the innate immune system, and they respond quickly to bacterial or fungal infections. Normally, neutrophils are able to produce an “oxidative burst” from the production of hydrogen peroxide from superoxide, which kills the bacteria. An enzyme called nicotinamide adenine dinucleotide phosphate (NADPH) oxidase, which is made up of six different proteins, accomplishes this process. These six components are gp91phox, p22phox, p47phox, p67phox, p49phox and Rac2. Mutations in any one of the components causes a different disease.

When the neutrophil is in a resting state before encountering any bacteria or fungus, these components are separate. Once a normal neutrophil is activated through encountering bacteria or fungus, these components combine together to initiate the “oxidative burst” process that kills the ingested organism. Mutations in any one of the components will lead to a defective NADPH oxidase that is incapable of producing the necessary compounds to kill the ingested invading organism.

Since neutrophils cannot effectively clear out the bacterial or fungal infections in CGD, the immune system forms granulomas to wall off the infections and contain them. The formation of the granulomas is the phenomenon that gives rise to the name CGD.

How Common Is CGD?

The prevalence of CGD is estimated to be around one in 200,000 live births. But, this statistic may be an underestimate because the disease is not systematically screened like severe combined immunodeficiency. The diagnosis can occur at any age because of different times of symptom manifestation, but generally the majority of diagnoses are made in children. However, autosomal recessive forms of the disease may present with a milder phenotype with delayed diagnosis into adulthood.

The most common form of CGD is the X-linked type, meaning that the defect is located on the X chromosome, and the condition is only seen in males. The X-linked form (gp91phox) accounts for 65 percent of CGD. There are three major autosomal recessive forms (requiring two copies of the same defect in order to manifest clinical presentation of disease), with the defect on chromosome 7 (p47phox) accounting for 25 percent of all known CGD cases. The remaining two forms of autosomal recessive CGD (p22phox and p67phox) each account for less than 5 percent of the known cases. There are no known autosomal dominant forms of the disease.

THE PREVALENCe OF CGD IS ESTIMATED TO BE AROUND ONE IN 200,000 LIVE BIRThS.

Signs and Symptoms of CGD

Most CGD patients present with symptoms in early childhood, but presentations later in adulthood also occur. As previously mentioned, later onset of disease can be the result of the autosomal recessive mutation. But, delayed diagnosis may also occur because symptoms are better controlled in developed countries with lower levels of bacterial/fungal exposure, as well as use of strong antibiotics for infections.

The predominant presentations of CGD are infections that can occur in the liver, skin, lungs and lymph nodes. In the U.S., CGD-related infections are generally from Staphylococcus aureus, Nocardia species, Serratia marcescens, Burkholderia cepacia and Aspergillus. In many other places in the world, tuberculosis, Bacillus Calmette-Guerin (BCG from vaccination) and Salmonella are common causes of infections in CGD patients. Other uncommon but CGD-defining bacterial infections are those from Chromobacterium violaceum and Francisella philomiragia. With the exception of Staphylococcus aureus, all
the other pathogens rarely cause disease in non-CGD patients. Fungal agents such as Aspergillus cause common infections in CGD patients, and initial presentation can be difficult to appreciate, leading to a delay in diagnosis.

Staphylococcal liver abscesses occur in a significant number of CGD patients, and they can be difficult to manage. The abscesses cause increases in liver enzymes and, over time, lead to structural complications such as elevation of pressures in the portal veins and abnormal enlargement of the liver and spleen. These complications are often associated with lower platelet counts that, coupled with worsening liver function, often lead to significant morbidity and mortality.

Female carriers of the X-linked form of CGD usually do not present with infections unless the level of normal neutrophils falls below 5 percent to 10 percent. Females can develop autoimmune complications of disease due to excessive inflammation such as discoid lupus (a chronic skin condition), oral ulcers and rashes caused by sunlight.

**Diagnosing CGD**

There are three main ways to test for CGD. The oldest and most well-known test is the nitroblue tetrazolium test (NBT) in which a special dye is used to stain neutrophils on a microscope slide. The cells that have normal reducing capacity to form superoxides form an insoluble bluish black compound, whereas the abnormal cells that have abnormal capacity to produce superoxides will not develop a color change. Therefore, a CGD patient’s neutrophils will not stain normally, leading to the diagnosis. However, this test is rarely performed today due to its inability to detect more subtle forms of disease and its difficulty in quantifying degree of disease severity.

The NBT has been largely replaced by the dihydrorhodamine test (DHR), which functions by testing the amount of hydrogen peroxide produced by neutrophils. The DHR is a flow cytometry test, meaning that it is a quantitative test based on the counting of response of individual cells. This test relies on the measurement of fluorescence (emission of light) following the oxidation of dihydrorhodamine by activated neutrophils. Inability to generate this fluorescence leads to the diagnosis of inadequate oxidative capacity of the neutrophil. In addition to diagnosing CGD, the DHR can also distinguish between the X-linked form and the autosomal recessive forms. The DHR can also detect female carriers of the X-linked form.

With the DHR test, neutrophils from normal individuals will have a low level of fluorescence in the resting state and a significantly elevated level of fluorescence following stimulation. Neutrophils from classic X-linked CGD will demonstrate no change in degree of fluorescence following stimulation. Neutrophils from autosomal recessive CGD will result in a wider variation and lower degree of fluorescence compared with neutrophils from normal individuals following stimulation. Neutrophils from carriers of X-linked CGD will demonstrate two peaks following stimulation, showing that these individuals possess both normal cells and abnormal cells.

The third method of detection of CGD is through direct genetic testing. For the X-linked form, the defect is in the CYBB gene on chromosome Xp21. The most common form of autosomal recessive form is from a defect in the NCF1 gene on chromo-
some 7. The other remaining autosomal recessive types are the result of defects of the CYBA gene on chromosome 16 and the NCF2 gene on chromosome 1q42.

**Treating CGD**

There are several approaches to treating CGD. Acute infectious and inflammatory complications need to be managed with the appropriate antimicrobials and immunosuppressive medications. Antimicrobials need to be selected based on their activity against the particular offending bacteria or fungus. Immunosuppressive medications need to be used to manage autoimmune complications. Liver abscesses in CGD need to be managed by a combination of both antibiotics and steroids for inflammation reduction. In general, steroids can help reduce the complications associated with the formation of granulomas, as well as the hyperinflammation seen in CGD following exposure to infectious agents. Biologic immunosuppressive medications should be avoided in CGD patients due to concern for increased risk of serious infections.

The cornerstone of CGD management is prevention. The recommended prevention regimen includes the use of antibiotics, namely trimethoprim-sulfamethoxazole (TMP-SMX), antifungal (itraconazole) and interferon gamma for immunomodulation. TMP-SMX should be administered at 5 mg/kg/day up to 320 mg in two divided doses. If the patient is allergic to sulfa drugs, then TMP, fluoroquinolones or a cephalosporin can be considered instead. Itraconazole should be administered at 100 mg/day for children under 13 years or less than 50 kg, and 200 mg/day for those older than 13 years or greater than 50 kg. Interferon gamma should be administered subcutaneously at 50 micrograms per meter-squared body surface area three times a week.

An additional therapy used in prophylaxis in CGD is interferon-gamma (Actimmune by Horizon Pharmaceutical). CGD is one of the first diseases to be treated with cytokine therapy in its routine management. Interferon gamma has been shown in a multicenter, international, double-blind, placebo-controlled study to reduce development of infections by 70 percent. It is believed that interferon gamma works because it increases superoxide production in neutrophils and macrophages to improve killing ingested bacteria. The benefit is most significant for young patients with the X-linked form of disease.

Immune globulin (IG) therapy is not typically used for the treatment of CGD. Historically, CGD was first described as recurrent infections in the setting of hypergamma globulinemia. The defect is not in the adaptive immune system or the production of antibodies. There have been rare case reports of some CGD patients with hypogammaglobulinemia, but it is uncertain whether those cases really represent two different deficiencies in the same patient. Some experts have used high-dose intravenous IG for the management of the severe inflammatory response seen in CGD patients, but again, the usage is rare, and there is no definitive evidence of efficacy.

CGD patients should receive all routine vaccinations, including live virus vaccines because the disease does not reduce the body’s immune response against viruses. However, CGD patients should never receive the BCG vaccine due to the potential of developing life-threatening BCG infection. This can be a concern in most countries around the world due to routine policies of BCG vaccination; however, it is usually not a concern in the U.S. because BCG vaccines are not generally administered.

The only approved form of curative therapy for CGD is hematopoietic stem cell transplantation. While transplant is a curative option, the majority of CGD patients have not been transplanted, and there are significant risks associated with stem cell transplant. Since each type of CGD arises from a single gene defect, there is significant research interest in the possibility of gene therapy as a potential cure.

**THE CORNERSTONE OF CGD MANAGEMENT IS PREVENTION.**

**CGD Prognosis**

The survival in CGD has been shown to correlate with residual oxidative ability of the neutrophils. Therefore, patients with a higher amount of residual oxidative capability will generally have better outcomes. This is consistent with the fact that autosomal recessive forms (higher residual oxidative capability) have better survival than the X-linked type. The overall survival of CGD has been improving, and is currently around 90 percent in 10 years.

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Regular activity at the appropriate intensity can help those suffering from these conditions.

Fibromyalgia (FM) and chronic fatigue syndrome (CFS), sometimes referred to as myalgic encephalomyelitis, are silent enemies that steal hours of productive, pain-free activity from their sufferers. Because neither condition can yet be established through definitive lab tests, and because their symptoms often mimic many other health conditions, the often long diagnostic process can be frustrating to patients. Unfortunately, anxiety is frequently amplified by family and friends telling patients that their pain and exhaustion is “all in their head.”

Many experts agree that the symptoms of FM and CFS are so similar that the two appear to be part of the same disorder. This belief is supported further by the observation that as many as 70 percent of people with either diagnosis also meet the criteria for the other. Interestingly, whether someone is diagnosed with FM or CFS might depend on the specialty of the doctor making the diagnosis. Rheumatologists tend to diagnose FM more, while immunologists are more likely to diagnose someone with CFS.

Despite a likely biophysiological link between the two diseases, there is enough variation when it comes to the effect of activity on their symptoms that it’s important to delineate their similarities and differences before discussing exercise.

Similar Conditions, but Not the Same

Those suffering from FM or CFS frequently experience debilitating fatigue, weakness and muscle pain; flu-like symptoms; sleep disorders; and cognitive-emotional challenges (e.g., forgetfulness, confusion, irritability/anxiety and/or depression). Men or women may be affected by either condition at any age; however, both pathologies typically affect the middle-aged and occur much more often in women than in men (two to four times more often in the case of CFS and as much as 10 times more often for FM).

Despite FM and CFS sharing common symptoms, more “pure” cases of each do occur. Patients with a clear diagnosis of FM typically experience more pain than those with CFS, possibly related to elevated levels of substance P (the neurotransmitter responsible for transmitting pain signals), and they demonstrate tenderness or pain in at least 11 of 18 distinct locations on their body referred to as “tender points.” Though a definite trigger has not been identified, it appears that FM develops in more people following a traumatic event, whereas CFS seems to develop more often following a viral infection (e.g., influenza, Epstein-Barr or herpesvirus 6).

Patients with a clear case of CFS do not demonstrate increased levels of substance P, nor do they have multiple tender points, but they do often exhibit an increase in RNase L, an antiviral enzyme found in cells. They also often have an inflammatory response to their condition, which may include swollen joints and glands or a fever — a phenomenon that isn’t observed in pure cases of FM. Though fatigue and nonrestorative sleep are symptoms of both FM and CFS, post-exertional malaise, or an intensifying of symptoms between 12 hours and 48 hours following exertion, is a greater risk
with CFS, whereas stiffness and immobility following inactivity is more universal in those with FM. Both of these observations come into play when discussing specific indications for exercise.

**Exercising with Fatigue**

Many of the principles regarding exercise with FM or CFS such as easing into a routine and pacing activity are important practices that have been discussed in previous *IG Living* articles. Yet, there are a number of concepts that are specific to one or both of these conditions.

One of the first and most important steps is to identify triggers that make patients’ symptoms worse. These could be stress, poor sleep, hormonal changes, poor diet, environmental pollution (e.g., air, noise or bright lights), cold or humid weather (especially with FM), recurrent infections (especially with CFS) and/or too much or too little physical activity. Before patients can expect to experience the benefits of exercise, they need to identify and eliminate or at least avoid triggers as much as possible. Many patients have stopped exercising after beginning a gentle routine because they believed that it was too much activity for them, when in actuality, one of the other triggers (not exercise) was worsening their symptoms.

**Before someone can expect to experience the benefits of exercise, they need to identify and eliminate or at least avoid triggers as much as possible.**

Once triggers have been identified, patients need to establish a baseline activity level. When doing so, all physical activity, including getting dressed in the morning, household chores, etc., should be considered exercise. I recommend that patients begin by going through their daily routine without performing any additional exercise, and that they record each activity in a notebook. If they can make it through the day while maintaining a subjective energy reserve of at least six out of 10, then that is their baseline for activity. If they can’t, they need to look at the list in their notebook and begin either eliminating or modifying activities one by one until they can. Patients shouldn’t worry if they are currently experiencing an exacerbation because it’s still important to establish a baseline of activity, even if that activity is extremely limited. I
actually suggest that patients establish at least two baselines: one when they are feeling their “typical selves” and one when they are experiencing an exacerbation. I say “at least,” because baselines for FM and CFS are frequently changing with noncontrollable, yet regular triggers like a woman’s menstrual cycle.

After having established a new baseline, patients can begin to increase their activity level by beginning a mild-to-moderate exercise routine (introducing one new exercise at a time), or by increasing their daily steps walked or daily activity level. These activities should be added to their notebook until they reach a point that they are unable to maintain their energy reserve at a level of at least six out of 10 by the next morning. I argue that no activity should cause a patient to dip below an energy level of four out of 10; however, when introducing activities, it is possible that levels may temporarily dip below a level of six out of 10. The important thing is that the level comes back up by the next day and that a bout of extended post-exertional fatigue is not initiated.

**Exercising with Pain**

Too much activity can lead not only to increased fatigue, but also to added muscle and joint pain. Conversely, and especially in the case of FM, not enough activity can cause the body to become sore and stiff. Avoidance of activity and exercise altogether leads to aerobic and muscular deconditioning that will, in turn, instigate a cycle of worsening symptoms and secondary health complications.

For those patients who experience pain that interferes with their day-to-day function, it may be beneficial to establish a baseline pain level similar to the baseline activity level mentioned previously. The same traditional zero to 10 scale may be used in most cases, with a zero representing no pain and a 10 being the worst pain imaginable. Activity should typically be limited to a level that does not increase pain past a five or a six out of 10, or which at least does not increase the baseline level by more than one or two points.

Anxiety or depression, factors that often influence pain perception, may make patients with FM or CFS poor self-evaluators. It’s important to note that pain is subjective, and patients should not be labeled as malingerers (i.e., exaggerators or fakers) or as babies or wimps because they aren’t able to “take it.” Such labeling is one of patients’ greatest fears and something that most certainly adds to any already existing anxiety, especially when it comes from those who should be part of their support network. That being said, if patients are reporting that their pain is an eight out of 10 as they calmly sit in front of you, it’s probably fair to say that either psychological factors are interfering with their report or those patients at least don’t have a good comprehension of the pain scale. If this is the case, there are several nonsubjective scales, including the FLACC (face, legs, activity, cry, consolability) scale, that can be appropriately administered by a family caregiver or medical professional to more accurately assess pain.

If patients have established energy and/or pain baselines from their daily activity, and they are asking how they can now increase their physical activity, light stretching and range-of-motion or isometric exercises are a good place to start. Exercise programs designed to improve aerobic capacity are not typically prescribed immediately upon initiating a new program, but if patients feel they are ready, light walking, wading in a pool or recumbent biking are the recommended activities.

**Special Considerations for Exercising with FM**

The National Institutes of Health states that regular exercise is one of the most effective treatments for fibromyalgia. This includes strengthening and (particularly) aerobic exercise as central components of the long-term program to help improve pain and overall well-being. More frequent, less vigorous activity is
also important. I prescribe five minutes of gentle activity (e.g., walking or moderate stretching) after every 20 minutes to 30 minutes of being sedentary.

The utilization of correct body mechanics and maintaining proper posture help to avoid prolonged stress to tender points and are other ways to significantly control pain. Though special bracing or Kinesio Taping techniques may help to provide some temporary relief by improving posture, a customized stretching and strengthening program can provide more lasting relief if adhered to. Many patients report that moist heat or massage to increase blood flow before exercise, and cold applied to joints to reduce inflammation after activity, are also successful strategies.

Special Considerations for Exercising with CFS

Several writers have suggested that patients with CFS should frequently monitor their heart rates to keep them below the anaerobic threshold (AT). AT, represented by a heart rate that is approximately 60 percent of maximum heart rate,6 is the level of exercise intensity at which the body stops using oxygen to metabolize carbohydrates, fats and proteins as its main source of energy and turns to anaerobic (i.e., oxygen-free) energy systems instead. Anaerobic metabolism produces waste byproducts (e.g., lactic acid) in the muscles and bloodstream faster than they can be carried away, and the body is unable to sustain activity much longer once it reaches this point. Rapid fatigue, prolonged malaise and delayed onset muscle soreness occur as side effects.

Patients with CFS may need to find their AT symptomatically and try to stay below the heart rate at that level rather than using the 60 percent of maximal heart rate rule of thumb. Some will discover that they can exceed their threshold quite easily with everyday activities so that tasks need to be paced better than they have been and, in some cases, stopped in mid-activity until heart rate can be controlled.

Improvement Is Possible

Despite these recommendations, as well as eating right and getting plenty of rest, exercise may still seem frightening to someone with FM or CFS. If more support is needed, cognitive behavioral therapy may be beneficial by teaching patients how to recognize and control their symptoms through behavioral strategies such as meditation and guided imagery.

The National Institutes of Health states that regular exercise is one of the most effective treatments for fibromyalgia.

As always, patients should celebrate what they are currently able to accomplish, however small it might seem, and not dwell on what they aren’t able to tolerate. That doesn’t mean that someone living with FM or CFS must be content with their plight, but they should be satisfied knowing that though it may come slowly, improvement can occur.

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Working with Chronic Illness: Patients’ Rights

The Americans with Disabilities Act and other laws provide protections for patients with chronic illness.

By Trudie Mitschang

FOR THOSE LIVING with an invisible chronic illness, the common accusation “You don’t look sick!” can be both frustrating and insulting. But, when that judgment finds its way into discussions regarding job performance, the need for special accommodations or medical leave, the repercussions can have far more serious consequences for both chronically ill patients and their families.

The Americans with Disabilities Act (ADA) was enacted by the U.S. Congress in 1990. Similar to the Civil Rights Act of 1964, the ADA is designed to protect individuals from any form of discrimination based on disability. In addition, it requires covered employers to provide “reasonable accommodations” that allow employees with disabilities to perform their jobs effectively, and it imposes accessibility requirements to address the needs of those with physical limitations.

In 2008, the original language within certain sections of the ADA was amended to address the need for a broader interpretation of the term “disability.” The changes were needed because in its previous draft, the courts had defined what constitutes a disability so narrowly that hardly anyone could qualify. The amended language now states that a disability is “any physical or mental condition that substantially limits a major life activity.”

What
constitutes a major life activity includes basic functions such as walking, reading, bending and speaking, as well as an array of bodily functions, including the immune system, cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions. As members of Congress explained, “The ADA Amendments Act rejects the high burden required [by the Supreme Court] and reiterates that Congress intends that the scope of the Americans with Disabilities Act be broad and inclusive. It is the intent of the legislation to establish a degree of functional limitation required for an impairment to constitute a disability that is consistent with what Congress originally intended.”

In layman’s terms, the ADA Amendments Act makes it easier for individuals seeking protection to establish that they actually have a disability. The amended guidelines cover the following individuals:

- Employees with a physical or mental impairment that substantially limits a major life activity
- Employees with a history of impairment (One cannot be discriminated against based on a previous disability.)
- Employees whom the employer regards as disabled (This protection is applicable if the employer discriminates against an employee based on its incorrect belief that the employee has a disability.)

ADA Coverage: What Is a Qualified Worker?

Title 1 of the ADA states that employers with more than 15 employees must provide reasonable accommodations to individuals with disabilities. While that language sounds somewhat inclusive, there are a lot of specific qualifications that could be left open to interpretation. For example, the ADA states that only “qualified workers” with disabilities are protected. Under the guidelines, a qualified worker with a disability is someone capable of performing the essential duties of the job in question, with or without a reasonable accommodation by the employer. For example, typical duties of a call center’s customer service representative would include answering phones, drafting correspondence and addressing complaints. An individual applying for that job would be expected to perform those tasks, and if needed or requested, an employer must provide a reasonable accommodation — an adjustment or modification that allows the employee to do the job.

According to the Reasonable Accommodation and Undue Hardship section of the ADA, any time an employee indicates that he/she is having a problem and the problem is related to a medical condition, the employer should consider it a potential request for accommodation.

Examples of reasonable accommodations under the guidelines include:

- An employee is having trouble getting to work on time because of medical treatments and needs an approved later start time.
- An employee needs six weeks off to get treatment for a back problem.
- A new employee who uses a wheelchair informs the employer that her wheelchair cannot fit under her desk in the office.
- An example of a request that does not meet the guidelines is:
  - An employee tells his supervisor that he would like a new chair because his present one is uncomfortable.

Although this is a request for a workstation change, it does not meet guidelines unless the discomfort is associated with a medical condition.

**Title 1 of the ADA states that employers with more than 15 employees must provide reasonable accommodations to individuals with disabilities.**

**Understanding Undue Hardship**

The ADA also protects employers, a fact many employees tend to overlook. The guidelines state that an employer is not required to provide a reasonable accommodation if doing so would create an “undue hardship.” An undue hardship is defined as something that presents significant difficulty or expense for the business. These factors determine whether an accommodation creates an undue hardship:

- the nature and cost of the accommodation
- the financial resources of the employer (larger companies can usually afford to do more than smaller ones)
- the nature of the business, including size, composition and structure
- accommodation costs already incurred in the workplace

If the cost of an accommodation threatens the financial viability of the organization, regardless of the reason, it’s probably an undue hardship and not required. However, according to the Equal Employment Opportunity Commission (EEOC), the
majority of accommodations cost less than $500. For most employers, that makes them reasonable and easy to implement.

To Tell or Not to Tell: Addressing the Issue of Invisibility

Primary immunodeficiency (PI) and other invisible chronic conditions present a unique challenge for both employees and employers. The challenges are highlighted by statistics from a study conducted by researchers at Cornell University’s Employment and Disability Institute. The study found that of the employment disability discrimination charges that were filed with the EEOC between 2005 and 2010, the most commonly cited conditions were invisible ones.

Despite the laws in place to protect them, many individuals with invisible illnesses such as PI choose not to disclose the illness, either during the hiring process or after diagnosis. Some fear being viewed with pity or being judged “incapable,” while others assume it will affect their chances of being hired or promoted. But experts say one of the main reasons it may be a wise decision to disclose any disability is for employees to put themselves in a position to request a reasonable accommodation. Obviously, if employees feel they can perform the essential functions of the job without accommodations, they may not want to disclose the nature of their illness. Some factors to consider:

- Under the ADA, employees must disclose they have a disability in order to be protected.
- Employees need to disclose only those medical conditions that require an accommodation.
- Employees do not need to disclose their disability to coworkers.
- Employees should be prepared to discuss with their employer what reasonable accommodations they need, including a modified work schedule, assistive devices and technology, or the need to sit rather than stand to perform a job.

Keep in mind that employees can disclose their chronic illness at any time during the hiring process. If they decide to disclose during the interview process, they should be prepared to provide examples of how they’ve performed job duties in the past, especially tasks related to the job for which they are interviewing. If they wait until an offer has been extended, the ADA states that the employer “cannot withdraw the job offer solely because you revealed you have a disability. Instead, the employer can withdraw the job offer only if it can show that you are unable to perform the essential functions of the job (with or without reasonable accommodation), or that you pose a significant risk of causing substantial harm to yourself or others.”

FAQs for Primary Immunodeficiency Patients

Q. How do I apply for disability?
A. When filing a claim, compile the most current records from your medical team such as your immunologist, rheumatologist, etc., and submit them at the time of the application. A letter from a physician documenting your inability to maintain full-time employment, and any supporting evidence such as lab findings, MRIs, X-rays is also helpful. It’s a good idea to be proactive and contact the disability examiner assigned to your case every few weeks to make sure they have all the requested information they need to process your claim. When asked to fill out a Disability Determination Services form, be as detailed as possible regarding your job duties, rate of pay, supervisory duties and physical limitations. Some individuals are also asked to submit to a medical exam. For more detailed information, visit www.ssa.gov.

Q. What is a good resource for information about the American Disabilities Act (ADA) and Family Medical Leave Act (FMLA)?
A. The Immune Deficiency Foundation recommends the Patient Advocate Foundation. The site has a resource titled First My Illness, Now Job Discrimination: Steps to Resolution. Within that resource is a section called Understanding the ABCs of the ADA and the FMLA that explains in detail what you need to know about these two laws. More information can be found at www.patientadvocate.org.

Q. Does the FMLA apply to infusions for an employee or an employee’s child?
A. The FMLA allows for leave to receive “continuing treatment by a healthcare provider,” which can include recurring absences for infusions. According to the law, employers with 50 or more employees must provide up to 12 weeks of unpaid, job-protected leave to employees who have worked for the employer for at least one year.

An employee’s children, spouse and parents are immediate family members for purposes of the FMLA. The term “children” does not include dependents over the age of 18 unless they are “incapable of self-care” due to a mental or physical disability that limits one or more of the major life activities defined by the ADA. To learn more, go to www.dol.gov.
Taking Leave When Needed

What happens if a chronic illness is diagnosed during tenure on an existing job? Employees may be entitled to medical and/or disability-related leave under both the ADA and the Family and Medical Leave Act (FMLA). In addition, state workers’ compensation laws have provisions that may apply.9

Workers’ compensation is a form of insurance that provides financial assistance, medical care and other benefits for employees who are injured or disabled on the job. Except for federal government employees and certain other groups of employees, workers’ compensation laws are administered at the state level. Because each state has its own system, coverage varies. As a general rule, workers’ compensation laws apply to all employers with one or more employees. In most states, all employees are covered. An on-the-job injury triggers coverage.

Under medical and disability-related leave rules, injured employees receive varying amounts of paid leave, depending on the state and the nature of the injury. If employees need time off because of a medical or disability-related issue, they may have rights under several laws at the same time. In certain circumstances, provisions of the ADA, the FMLA and workers’ compensation laws can apply.9 For example, a workers’ compensation injury that requires hospitalization or incapacitates an employee for more than three days and requires continuing treatment by a healthcare provider generally qualifies as a serious health condition under the FMLA. If the injury causes a permanent mental or physical impairment that substantially limits a major life activity, that same employee could be entitled to additional leave as a reasonable accommodation under the ADA.

In addition, several states have enacted their own family and medical leave laws, some of which provide greater amounts of leave and benefits than those provided by the FMLA. State laws may also apply to employees who are not eligible for benefits under the FMLA. In general, when employees are covered by both federal and state family and medical leave laws, they are entitled to the greater benefit provided under the different parts of each law.

Filing a Charge of Discrimination

If employees think an employer has denied them a job or an equal opportunity to apply for a job based on a visible or invisible disability; has refused their request for reasonable accommodation; or has made illegal medical inquiries or required them to take an illegal medical examination, employees should contact the EEOC. Timing is important, because employees are required to file a complaint of discrimination within 180 days of the alleged offense. Employees may have up to 300 days to file a charge if a state or local law provides relief for discrimination on the basis of disability, but to protect their rights, it is best to contact the EEOC as soon as possible to discuss all options.

UNDER MEDICAL AND DISABILITY-RELATED LEAVE RULES, INJURED EMPLOYEES RECEIVE VARYING AMOUNTS OF PAID LEAVE, DEPENDING ON THE STATE AND THE NATURE OF THE INJURY.

According to the EEOC, if it is determined that an employee has been discriminated against, that employee is entitled to a remedy that will place him or her in the position he or she would have been in if the discrimination had never occurred. This means the employee may be entitled to hiring, back pay or reasonable accommodation. The employee may also be entitled to reimbursement for attorney’s fees.

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.

References
JASMINE AHUMADA was an active 27-year-old with a career she loved when her life took a dramatic turn seven years ago. After chronic illness and a serious staph infection left her hospitalized and grappling for answers, Jasmine was eventually diagnosed with common variable immunodeficiency (CVID). Unable to work, the 35-year-old California resident began to dabble in makeup artistry, and discovered a new talent that she’s using to raise awareness for patients in the primary immunodeficiency (PI) community.

Trudie: Tell us about life before CVID.

Jasmine: Prior to being diagnosed with CVID, I was a healthy, active young woman. I was in the process of buying my first home, in a steady relationship and working at a job that I loved. For almost 10 years, I worked as an instructor at a day program for developmentally disabled adults, and I loved it with all my heart. During my last few years there, I was chronically ill but didn’t know why, especially since previously I had always been healthy. Even as a child, I lived a normal, active life with very few medical issues. Suddenly, I found myself in my mid-20s with constant infections and medical problems.

Trudie: When did you suspect something was seriously wrong?

Jasmine: I suspected something was wrong when I realized that my doctor visits were getting more and more frequent. It seemed like I was sick all the time. I would get infections that wouldn’t go away, I was feeling drained, and I just lived with that very "unwell" feeling. At first, I was blaming my illnesses and infections on the fact that I worked out in the community and in a school-type setting where people were often sick.

Trudie: When were you finally diagnosed?

Jasmine: When I was 27, I developed a methicillin-resistant Staphylococcus aureus (MRSA) infection on my leg. The infection was very serious and landed me in the hospital for about a week. After healing from that, I continued to get small staph infections randomly on different parts of my body. While this was going on, I was also suffering with lung infections and pneumonia. I went to my primary care physician literally every other day. I would tell him I feel unwell and that something must be wrong. Finally, after many appointments with him, he sent me to an infectious disease specialist. It was that doctor who actually listened to me and ran the one test that confirmed I was making little to no antibodies.

Trudie: What is your treatment plan?

Jasmine: I receive intravenous immune globulin (IVIG) at my local hospital once every four weeks. IVIG has changed my life for the better! Now, I rarely get infections, and I am sick less frequently. I have the support of my medical team, as well as my family and friends.

Trudie: How did you get involved with face and body art?

Jasmine: I have always been into beauty and makeup, and through television and social media outlets, I was seeing this face and body art more and more. I became interested in it and decided to try it out for myself. I thought it would be fun, but I had no clue that I would actually be pretty good at it! As I got into it, I realized that it helped fill a void I didn’t even know was there. Before experimenting with face and body makeup less than a year ago, I had never done any type of art.

Trudie: Your work is beautiful and very dramatic. How do you promote it?

Jasmine: I have recently found the
wonderful world of Instagram, and that’s where I promote all the looks I do. Instagram has a large, supportive and talented community of artists like me. I also have a Facebook page where I share my makeup with family and friends.

Trudie: How are you using your art for advocacy?

Jasmine: I’ve created special images that represent the primary immunodeficiency disease patient experience. I created a look for Invisible Illness Awareness Week that depicts the way my immune deficiency makes me feel on the inside, though I do not often appear that way on the outside. I also painted on my implanted power port where I receive my monthly IVIG infusions. I wanted to show a visual of what my port looks like; you can’t see it by just looking at me, but it is now very much a part of me. Another image I’m proud of is called the “golden zebra,” which is also representative of the PI community. I realize some images may be shocking to some, simply because I tend to always have a wonderful attitude and outlook on life.

Trudie: What are your goals for the future?

Jasmine: The biggest thing that CVID has taught me is that I am stronger than I ever imagined I could be. It has taught me that no matter what this disease throws at me, I can handle it. It has also taught me to be even more grateful and compassionate. I feel more blessed and thankful than I ever did before. I see the world in a whole new light. Without this diagnosis, I’m not sure I’d view life the same as I do now.

Trudie: What advice do you have for others?

Jasmine: The best advice I could give to somebody with CVID is to remain positive. Oftentimes our attitude will directly determine what our day will be like. Positive thoughts equal a happier life. It’s easy to get caught up in how horrible you feel, what you’re unable to do and what you don’t have. The more important thing to remember is that you are blessed with so many things. You just have to think about how good you do feel, what you are able to do and what you do have. I do not let my disease shape who I am or how I live. I am blessed.

Trudie Mitschang is a contributing writer for IG Living magazine.

Editor’s note: See more of Jasmine’s makeup artistry by following her on Instagram at @Butterflyjasmine49.
It’s hard to believe that I have been receiving immune globulin (IG) therapy for over 11 years. It doesn’t seem that long ago that I was diagnosed with common variable immunodeficiency after a lucky visit with a doctor whom I went to see because I was suffering from yet another sinus infection. For years, my “regular” doctor, who was confused by my recurrent infections, kept prescribing one antibiotic after another. Yet, in my gut, I knew that something was seriously wrong.

I described my medical history to “Dr. Stranger” and asked him if he could draw some labs. It was only three hours after I left his office when I received a phone call from him telling me that in addition to the regular labs that had been drawn in the past, he added a “quantitative gamma globulin” panel (whatever that meant), which showed I have an immune deficiency. He explained in simple terms that my body is not producing enough immunity to fight off infections, which is why I had been having so many.

I was so happy! It seems like a strange response to a doctor telling me I have an incurable chronic illness, but I had an answer. Finally, I knew I wasn’t crazy! Then, I was scared, anxious, relieved, panicked and every other emotion you can think of. Of course, I then went right to “Dr. Google” to help me understand what I was dealing with. It wasn’t more than one week later that I met my immunologist, and one week after that, I received my first intravenous IG infusion.

I adapted quickly to my new normal. I had complete faith this treatment would help me, and it did. But once the whirlwind calmed, I felt alone in my illness. I wanted to find others who were like me. I wanted to find friends and other patients who could give me a glimpse at what the future might hold. It wasn’t easy at first, so I turned to the doctor who diagnosed me. While that may seem a little out of the ordinary, he was a great support to me in the beginning, and he still is. I can go to him anytime just to talk and ask questions. He is one of those doctors no one believes exists. I call him a Zebracorn (unicorn zebra doctor)!

It took some time, but I was able to find an amazing group of friends who have a wealth of information and experiences. Some I have had the privilege to meet in person numerous times. I even went to a fellow zebra’s wedding this year! The feeling of community has become so important to me. The comfort of knowing that there are others out there who have a complete understanding and empathy for what I am experiencing is priceless.

Today, I went back to “Dr. Google” and typed in: “What do you call a group of zebras?” I needed a name for my people. It turns out a group of zebras is called a dazzle. How fitting! Our stripes may confuse and overwhelm some, but together, we do amazing things. Since my diagnosis 11 years ago, my life has been “dazzled” by so many wonderful zebras.

Ever Fecske Mazza was diagnosed with CVID and interstitial lung disease in 2004. She is a mom of a sweet little boy named Boston, and loves every minute of it! She lives in Los Angeles, Calif, with her husband, and when she isn’t changing diapers and playing with her son, she enjoys wedding planning, baking, flower arranging, cooking, shopping and anything that sparkles!
What You Should Say

By Ilana Jacqueline

MAYBE YOU DON’T mean what you just said. Maybe you’re lying through your teeth. But, sometimes, that’s just how you’re expected to react in social situations. Didn’t your momma ever teach you how to say, “Thank you for the underwear, Aunt Judy,” when all you wanted was a Destiny’s Child CD?

With chronic illnesses, we are constantly facing friends who disagree with our treatment plan, think we’re going through a phase, or simply do not understand the gravity of how our disease impacts our life. That’s OK. No one says the right thing all the time, so it doesn’t make these friends bad people. It is, however, up to you as a patient to educate them and to have tougher skin to handle remarks that are going to rub you the wrong way.

Here are some statements that you may have heard, reactions you probably felt like giving, but didn’t, and my advice for some simple responses to help you wriggle out of awkward conversations about your disease.

A well-meaning friend might say:
“I read about your disease on the Internet, and I learned that elephant’s blood is actually the cure. Doctors just don’t want you to know because then you’ll feel better and they’ll have to see you less often.”

What you might be thinking:
“Are you drunk? Let me guess: Your source for that is Yahoo Answers? Don’t you think if it were as easy as drinking a large animal’s blood that I would have bought a gallon at Costco by now?”

What you should say instead:
“Thank you, I’ll have to check that out. I do stay involved in my disease community’s research, so if that pops up, I’ll have to talk to my doctor about it. Also, at this point, my condition has no actual ‘cure,’ but there are always new treatments and clinical trials coming out.”

An innocent, but concerned, friend might say:
“I heard you were having an immune deficiency yesterday. Are you feeling better today?”

What you might feel like saying:
“Did I recover from my disease over the last eight hours? No, I did not. How’s that whole world peace thing going since Thursday? All resolved now?”

Here’s what you should say instead:
“Physically, I don’t feel much better today, but I’m coping with it a little better each day.”

A new friend might suggest:
“That disease is exactly like (insert disease name that is so far away from the spectrum of your disease, they’re not even on the same medical planet), right?”

What you might feel like saying:
Nothing. Because you’ve lost faith in all humanity.

What you might say instead:
“Actually they’re not really the same sort of thing. My disease mostly affects my (organ), whereas that disease affects the (organ). You should Google it later; you might find it interesting.”

The spread of misinformation is often caused by ignoring inaccurate comments about your condition. While you might feel offended and want to snap at a comment, try to remember that it is your responsibility to educate others — if you want to interact with them on a regular basis. If you don’t feel like getting into all the details, you can suggest they find sources on or offline (hey — you could even pass along this magazine!).

ILANA JACQUELINE is a 26-year-old dysautonomia and primary immune deficiency disease patient from South Florida. She’s been writing professionally since 2004 on everything from health and wellness to celebrities and beauty. Her blog www.letsfeelbetter.com is both a personal collection of anecdotes about life with chronic illness, as well as a resource for patients of all ages.
How to Homeschool a Chronically Ill Child

By Jessica Leigh Johnson

Because of frequent sickness and multiple doctor appointments, children who suffer from chronic illness may miss school more than their peers. These absences from class can cause them to fall behind in their schoolwork, and eventually, their grades may suffer. One option for parents facing this situation is to remove their child from a conventional educational setting and homeschool him or her instead.

For children who suffer from chronic health problems, homeschooling offers great advantages. It removes the child from a crowded classroom where germs spread easily, and it offers flexibility for parents to schedule treatments and appointments without worry about what the child will miss at school. However, the decision to homeschool is a major one, and only the first of many choices that need to be made in regard to the child’s education. Where do parents begin when navigating these uncharted waters of homeschooling their chronically ill children?

Check out state homeschool laws. After parents have made the decision to homeschool, the very first step they should take is to acquaint themselves with the homeschool laws and requirements in their area, which vary by state. Using any major search engine, parents can easily find this information on the Internet. Understanding what is required in their state will enable parents to homeschool legally, and with greater confidence.

Make a plan. Next, parents should make a long-term plan, including the specific goals they have for their child’s education. How many years do the parents plan to homeschool? Does the child plan to attend college after high school and, if so, how will parents ensure that the child is adequately prepared for higher education? What possible career path might the child choose? By the end of his or her time in school/homeschool, what knowledge and set of skills do parents wish the child to have — not just in order to function well in their future careers, but to function well in life? Addressing these questions in advance may help parents fine-tune their child’s education by seeking out the resources (which include curriculum) and methods needed to follow through with their plan.

Choose a homeschool curriculum. Once a plan has been devised, parents should choose a curriculum that best meets the plan’s goals. Many parents are overwhelmed by the number of options available. Should they use traditional textbooks or homeschool-specific curriculum? Online-only material or correspondence courses?

One benefit of homeschooling is that parents are able to choose a curriculum that is best suited to the child’s individual academic strengths and interests, as well as the values of the family. For example, would the child thrive studying a curriculum geared toward the arts? Or one that focuses heavily on math and science? Would a faith-based curriculum, or a strictly secular one, suit the needs of the family? For parents who don’t have much time to devote to individual lesson planning, choosing a curriculum with fully planned lessons is important.

To narrow down the search and find the curriculum best suited to both the child and family, there are helpful guides written by experienced homeschool moms. Two highly recommended guidebooks are Mary Pride’s Complete Guide to Getting Started in Homeschooling and Cathy Duffy’s 101 Top Picks for Homeschool Curriculum.

Create a homeschool schedule. Although the traditional school schedule runs during the day on weekdays only, homeschooling can be more flexible, which is why some parents of chronically ill children choose this path. This flexibility also comes in handy in families where both parents work, or in single-parent households. While it would be ideal if one parent had the ability to stay home with
the chronically ill child to conduct and supervise homeschooling, this isn’t always possible. Should one parent quit his or her job to take on the role of teacher? When and where does the homeschooling take place if parents can’t afford to stay home? In families with chronically ill children, where health insurance is vital and medical costs are high, sometimes it isn’t feasible to give up one income or health benefits. Finding a solution may require some creativity and juggling of schedules, but if parents feel homeschooling is the best option for their child, there are ways to make it work:

- Parents should examine their work schedules and determine when they can carve out time for homeschooling. If both parents work during the day, Monday through Friday, school could take place on the weekends and in the evenings. Alternately, if parents work nights or evenings, school would take place during the day. Homeschooling parents don’t need to follow a traditional school schedule. Flexibility is key.
- One drawback to pulling children out of a traditional school setting to homeschool when both parents work nine-to-five jobs is the sudden need for daily childcare. Parents will need to find a trusted adult to care for their school-age child, even if this person isn’t the one conducting their schooling.
- If parents are determined to homeschool but know it is not feasible with their current job situation, it may be necessary to seek out new employment that will better accommodate a homeschooling schedule. Possibilities include flex time work or telecommuting. Or depending upon their current jobs, parents could switch shifts: one works evenings, while the other works days. These solutions may not be ideal, but some major lifestyle changes may be necessary to accomplish the goal of homeschooling, especially if the child’s health and/or academic success is at stake.

Create a support system. Beginning the homeschool journey is a challenge for parents, no matter what motivated them to choose this path. They can often feel alone in the process, especially the parent who left the workforce to oversee his or her child’s education. It’s possible they may even encounter criticism for their decision from well-meaning family and friends. When the child is no longer in a traditional school setting, parents and children alike may feel isolated, missing the interaction from the other students and families that once surrounded them on a daily basis. It is important for parents to find individuals and organizations to support and encourage them throughout the transition process, and well into their homeschooling journey.

The first step toward building this support system is for parents to contact other homeschooling families in their area to join a local homeschool support group. Connecting with other homeschooling parents is a great way to learn what works and what doesn’t, and why. It also provides opportunities for homeschooled children to get together for much-needed social interaction outside of the traditional school setting. Many larger towns have homeschool seminars and curriculum fairs where parents can look at various options firsthand, rather than online. To find a support group or state homeschool convention, visit the Homeschool Legal Defense Association’s website at www.hslda.org.

The decision to homeschool is a major one, and only the first of many choices that need to be made in regard to the child’s education.

When parents choose the path of homeschooling, it can seem like a lonely road at first, especially if the child is chronically ill, and already facing struggles that have nothing to do with school. But, it is encouraging to know that hundreds of families are homeschooling children with special health needs. Parents might even find that when their chronically ill children are educated at home, where parents can offer them individualized education, flexibility, encouragement and support, they often break through the barrier that has kept them from making significant progress in a traditional school setting.

JESSICA LEIGH JOHNSON is a stay-at-home mom and mother of four kids, three of whom have X-linked agammaglobulinemia. She is a member of American Christian Fiction Writers and has written one book about the loss of her son to a primary immunodeficiency.

Sources
Avoiding Germs at the Gym

By Trudie Mitschang

IT’S WELL KNOWN that exercise is part of a healthy lifestyle, and for many of us, that can mean hitting the gym a few times a week. Unfortunately, gyms tend to be hotbeds of germ activity (did you know norovirus, which causes stomach pain, vomiting and diarrhea, can survive for a month on the surface of exercise machines?). As a primary immunodeficiency disease patient, you know exposure to bacteria and viruses can create a major health hazard. To help you stay safe during your cardio and strength training routines, we’ve identified some of the germ breeding grounds associated with health clubs, gym bags and workout accessories.

Avoid Foot Fungus

Floors in locker rooms and shower stalls are rife with germs. Even a tiny cut on your foot could expose you to a fungus that leads to an infection like athlete’s foot. Plan to wear flip-flops in the shower so your feet are never in direct contact with the floor. That includes trips to the pool, steam room and sauna, too, since a fungal infection can happen anywhere when you’re barefoot.

Disinfect Your Bag

Your gym bag likely gets tossed around a lot. But how often do you actually clean it inside and out? When you think about it, your gym bag has likely been in the trunk of your car, set on the ground and locker room floor, and possibly even the public bathroom. Then there’s all the dirty, sweaty clothes that get thrown inside of it. It’s a smart idea to keep a bottle of disinfectant spray in your car or gym bag that you can use to spritz the bag’s interior and exterior surfaces on a regular basis.

BYOM (bring your own mat)

Sharing mats during yoga or for floor exercises can put you at risk for fungal infections. The best option is to bring your own yoga or workout mat and clean it regularly (just like your gym bag). If you do use a mat at the gym, clean it first with an antibacterial wipe, and place a clean towel on top of it before lying down.

BYOB (bring your own water bottle)

It’s important to stay hydrated while working out, but using a communal water fountain is not a great idea. While it’s gross to contemplate, fellow gym-goers might accidentally hit the fountain’s spout with their mouths (some may even spit in it), exposing those who come later to all types of potential germs. Bringing a reusable water bottle is both economical and safe. Also, avoid contaminating your own water source by choosing a bottle that has a spout you can easily pull open with your mouth instead of your hands.

BYOT (bring your own towel)

Designate a towel just for the gym and mark one side with an “X” in permanent ink. Then, make sure only that side comes in contact with germy gym equipment. Use the unmarked side to wipe sweat. It’s also a good idea to bring a separate towel for showering. Consider a special antimicrobial one available at sporting goods stores.

Keep Your Distance

Crowded fitness classes make it easy to inhale germs, especially during cold and flu season. When possible, try to keep approximately two arm lengths between yourself and anyone else in a group class.

Mind the Machines

Treadmills, ellipticals and bikes are obvious breeding grounds for germs. Wipe down machines, handles and seats thoroughly with disinfectant before and after you use them.

Anti-Germ Check List

Follow this quick checklist to avoid germ exposure while working out:

• Cover any cuts or broken skin with a bandage before you go to the gym.
• Wash your hands before and after your workout.
• Wipe down machines before and after use.
• Don’t shave at the gym or immediately before going there.
• Whenever possible, shower at home after your workout.
• Keep dirty clothes and sneakers in separate gym bag compartments, or place them in a plastic bag.
• Wipe down your gym bag with a disinfectant spray, and wash gym clothes after each use.

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.
**Verve Microfiber Suede Fitness Towel**

The microfiber material of this towel impedes the growth of bacteria and other microbial life. The result is a towel that doesn’t smell or transmit unwelcome germs. At 20-by-40 inches, the size is large enough for adequate cover but small enough to be portable. $17.97; Amazon.com

**Vertico Shower Sandal**

This versatile sandal is made to be lightweight and quick-drying. The closed-cell EVA construction reduces the amount of water absorbed and can help reduce the chance of ringworm, athlete’s foot, tinea and other fungi. $10.99; Amazon.com

**Gaiam 3mm Two-Color Yoga Mat**

Designed to give the appearance of the calm ocean or the sky, the Gaiam reversible yoga mat’s soothing colors and non-slip surface are designed to combine relaxation and traction to enhance workouts. A non-slip surface ensures a secure grip. $21.99; dickssportinggoods.com

**Apera Fit Pocket**

This is a smart way to keep your gym bag organized and germ-free. It is available in three colors (electric lime, titanium and arctic blue) and comes with antimicrobial protection that resists the formation of bacterial odor inside and out. The water-resistant material is machine-washable. $9.60; aperabags.com

**Brita Sport Water Filter Bottle**

This twin pack provides a portable water filtration system for workouts and more. The soft-squeeze BPA-free bottle allows users to grab water from the water fountain or sink. It comes with two 20-ounce soft-sided water filter bottles with two filters. $12.92; Walmart.com

**Wet-Nap Antibacterial Hand Wipes Packets**

These portable and fresh-scented wipes offer on-the-go disinfecting, from killing germs on gym bags and equipment to keeping hands clean. They come in a package of 24. $5.49; Walgreens and other retail drug stores
**BOOK CORNER**

**Autoimmune Disease: Guide to Understanding and Treating Autoimmune Disease with Nutritional Strategies for Alleviating and Reversing Autoimmune Disorders**

Author: Amanda Hollingsworth  
Publisher: Amazon Digital Services

This book is written to help individuals understand how autoimmune disorders usually develop and what the common risk factors are. Readers will learn several treatments, approaches and strategies for how to cope with these chronic diseases. Chapters include Attack of the Immune System; Possible Causes, Symptoms and Diagnoses; The Common Autoimmune Diseases; Risk Factors and Contributing Agents; Treating the Disorders and Managing the Symptoms; Proper Nutrition vs. Autoimmune Diseases; and Natural Ways to Reverse the Autoimmune Diseases.

**Tiny Buddha’s Guide to Loving Yourself: 40 Ways to Transform Your Inner Critic and Your Life**

Author: Lori Deschene  
Publisher: Conari Press

In *Tiny Buddha’s Guide to Loving Yourself*, the author shares 40 unique perspectives and insights on topics related to loving yourself, including realizing you’re not broken, accepting your flaws, releasing the need for approval, forgiving yourself, letting go of comparisons and learning to be authentic. It features stories selected from hundreds of TinyBuddha.com contributors that provide an honest look at what it means to overcome critical, self-judging thoughts to create a peaceful, empowered life.

**The Hidden Truth: Deception in Women’s Health Care: A Physician’s Advice to Women — and All Who Care for Them**

Author: John T. Littell, MD, FAAFP  
Publisher: Amazon Digital Services

In a guidebook tailored for both women and men, a seasoned doctor combines facts and advice relevant to women and their families that will empower them to make informed decisions about future healthcare. Dr. John Littell, a family physician with more than 25 years of experience that includes obstetrics and gynecology, shares insight about controversial issues in women’s healthcare that range from HPV vaccination in children to the diagnosis and treatment of HPV-related disease to the numerous choices related to contraception and family planning. With an emphasis on natural options, Dr. Littell includes guidance and case studies related to common gynecologic health issues encountered by teenagers and women throughout their reproductive lives.

**Stiehm’s Immune Deficiencies**

Authors: Kathleen E. Sullivan, MD, PhD, and E. Richard Stiehm, MD  
Publisher: Academic Press

**Stiehm’s Immune Deficiencies** focuses on immunodeficiencies in children and adults. The book covers the many advances in the study of immunodeficiency with 62 chapters dedicated to topics such as newly described syndromes, genetic diagnosis, molecular abnormalities, newborn screening and current therapies. In addition, it provides practical guidance to practitioners dealing with the day-to-day issues of diagnosis and management of immune deficient patients.
For a more comprehensive list of resources, visit the Resources page at IGLiving.com.

**Ataxia Telangiectasia (A-T)**

**WEBSITES**
- A-T Children’s Project: www.atcp.org

**Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)**

**WEBSITES**
- GBS/CIDP Foundation International: www.gbs-cidp.org
- The Neuropathy Association: www.neuropathy.org

**Evans Syndrome**

**ONLINE PEER SUPPORT**
- Evans Syndrome Research and Support Group: www.evanssyndrome.org

**Guillain-Barré Syndrome (GBS)**

**WEBSITES**
- GBS/CIDP Foundation International: www.gbs-cidp.org
- The Neuropathy Association: www.neuropathy.org

**Idiopathic Thrombocytopenic Purpura (ITP)**

**WEBSITES**
- ITP Support Association – UK: www.itpsupport.org.uk
- Platelet Disorder Support Association: www.pdsa.org

**Kawasaki Disease**

**WEBSITES**
- American Heart Association: www.heart.org/HEARTORG/Conditions/More/CardiovascularConditionsOfChildhood/Kawasaki-Disease_UCM_308777_Article.jsp#T1T2boeFWE0
- Kawasaki Disease Foundation: www.kdfoundation.org
- KidsHealth: kidshealth.org/parent/medical/heart/kawasaki.html

**Mitochondrial Disease**

**WEBSITES**
- United Mitochondrial Disease Foundation: www.umdf.org
- MitAAction: www.mitaaction.org

**Multifocal Motor Neuropathy (MMN)**

**WEBSITES**
- 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
- 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**
- Genetic Alliance: www.geneticalliance.org

**Myositis**

**WEBSITES**
- The Myositis Association: www.myositis.org
- International Myositis Assessment and Clinical Studies Group: www.niehs.nih.gov/research/resources/collab/imacs/main.cfm

**ONLINE PEER SUPPORT**
- The Cure JM Foundation: www.curejm.com
- Michigan Immunodeficiency Foundation: www.facebook.com/groups/108048062584350
- Myositis Support Group: www.myositisupportgroup.org
- Myositis Support Group – UK: www.myositis.org.uk

**Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANdAS)**

**WEBSITES**
- P.A.N.D.A.S. Network: pandasnetwork.org
- Midwest PANS/PANDAS Support Group: www.giveforkids.com

**Peripheral Neuropathy (PN)**

**WEBSITES**
- Neuropathy Action Foundation: www.neuropathyaction.org
- Western Neuropathy Association: www.pnhelp.org
- Texas Chapter of the Neuropathy Association: www.handsfeetheart.org

**Primary Immune Deficiency Disease (PI)**

**WEBSITES**
- Immune Deficiency Foundation: www.primaryimmunedef.org
- Jeffrey Modell Foundation: www.info4pi.org
- American Academy of Allergy, Asthma & Immunology: www.aaaai.org
- International Patient Organisation for Primary Immunodeficiencies (IPOPI) — UK: www.ipopi.org
- New England Primary Immunodeficiency Network: www.nepin.org
- Rainbow Allergy-Immunology: www.uhospitals.org/rainbow/services/allergy-immunology

**ONLINE PEER SUPPORT**
- IDF Common Ground: www.idfcommonground.org
- IDF Discussion Forum: idffriends.org/forum
- IDF Friends: idffriends.org
- Jeffrey Modell Foundation Facebook Page: www.facebook.com/JMFworld
- Michigan Immunodeficiency Foundation: www.facebook.com/groups/108048062584350

**Scleroderma**

**WEBSITES**
- Scleroderma Foundation: www.scleroderma.org
- Scleroderma Research Foundation: www.srfcure.org
- Scleroderma Center: www.hopkinsmedicine.org/rheumatology/clinics/scleroderma_center.html

**ONLINE PEER SUPPORT**
- Scleroderma Support Forum: curezone.com/forums/t.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
- Genetic Alliance: www.geneticalliance.org
- Living with Stiff Person Syndrome (personal account): www.livingwithsp.com
- Stiff Person Syndrome: www.stiffpersont syndrome.net
Enjoy life’s moments.
Sign up today!

Call 1-855-250-5111
or visit MyIgSource.com/ig
to enroll in the program.

This program is available to all patients and caregivers regardless of treatment.
This program does not provide medical advice. Please consult with your doctor for medical advice and to determine the appropriate treatment for you.
Support for living hands-on

Life is full of beginnings, and a primary immunodeficiency (PI) diagnosis is one of them. MyIgSource is here to support you throughout your PI journey, allowing you to enjoy life’s moments.
Take Control of your flu vaccine supply

with MyFluVaccine.com easy online ordering

YOU PICK THE DELIVERY DATE » Conveniently secure YOUR best delivery date(s)
YOU PICK THE QUANTITY » Choose from a broad portfolio of products
WE SAFELY DELIVER » Count on FFF’s secure supply channel with Guaranteed Channel Integrity™