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About IG Living
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Treatment Approaches for Chronic Illness

CHRONIC ILLNESSES are the leading cause of death and disability worldwide, accounting for almost 60 percent of all deaths and 43 percent of the global burden of disease. While much emphasis is correctly given to medication for these illnesses, treating chronic illness doesn’t stop at drug therapies.

For example, over the years, the standard treatment for PANDAS (pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections) has been antibiotics, immunotherapy and therapeutic plasma exchange. But, as Dr. Rodney Lusk, who specializes in PANDAS research, discusses in his article “Treating PANDAS,” there is recent data (yet unpublished) to suggest that two surgical interventions — tonsillectomy and adenoidectomy — may be more effective than medicinal therapies, especially when performed during the early onset of symptoms. While these interventions are not yet recommended as routine therapy, their results are supported by previous literature, and with additional study, they hold hope for more successful treatment of this disorder.

Peripheral neuropathy (PN) — a condition resulting from damage to the peripheral nervous system that causes numbness, muscle weakness and burning pain — affects some 20 million people in the U.S. Fortunately, individuals suffering from PN can help to care for themselves by exercising, which is shown to manage the symptoms and, in some cases, improve them. For instance, in a pilot study of a 10-week supervised aerobic and resistance exercise program, researchers found significant improvements in measures of pain, neuropathic symptoms and cutaneous fiber branching. In his article “Exercising While Living with Peripheral Neuropathy,” physical therapist Matthew Hansen illustrates key exercises for flexibility, strength and balance to help control neuropathic symptoms.

In fact, exercise can benefit those navigating through any type of chronic illness. In our article “Exercise and Immune Disease,” you’ll find tips for beginning an exercise program and making it fun. In addition, we recommend some products that support fitness routines.

Another proactive approach to care involves patients understanding why tests are performed and what they mean. Starting with the basics, in “Routine Lab Reports: What Do They Mean?” Dr. Bob Geng explains the two most common routine lab tests, their purpose and what they can reveal to help doctors uncover complications in their patients’ health. In the next issue of IG Living, Dr. Geng will explain lab tests specific to immune deficiencies.

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

Ronale Tucker Rhodes, MS

Biologics vs. Biosimilars: The Controversy

By Abbie Cornett

MANY PATIENTS WITH chronic illnesses such as common variable immunodeficiency, myasthenia gravis, myositis and neuropathies require treatment with biologic drugs. Biologics are complex medical products derived from organic matter. An example of a biologic is immune globulin, which is derived from human plasma. Currently, there is a movement to allow the substitution of biologics with drugs, known as biosimilars, that are less expensive and have a similar makeup. Unlike generic drugs that contain active ingredients identical to their small molecule reference products, biosimilars are close copies of the original biologics, but they are not exactly the same. Biologics have very large molecule structures leading to much higher development complexity for biosimilars, which renders biosimilars unique.¹

On March 6, the U.S. Food and Drug Administration (FDA) approved Zarxio (filgrastim-sndz for the treatment of infection in certain cancer patients undergoing chemotherapy), the first biosimilar in the United States. The approval of this first biosimilar was made possible by the Biologics Price Competition and Innovation (BPCI) Act within the Patient Protection and Affordable Care Act, which allows FDA to declare a biosimilar interchangeable provided that it is expected to produce the same results in all patients and, with continued use, the safety and efficacy risks are no greater if a patient were to be switched to a biosimilar than if they had stayed on the innovator drug. Proponents of biosimilars argue that they will improve access to care for patients and save billions of dollars. According to FDA Commissioner Margaret A. Hamburg, MD, “Biosimilars will provide access to important therapies for patients who need them. Patients and the health care community can be confident that biosimilar products approved by the FDA meet the agency’s rigorous safety, efficacy and quality standards.”

But the substitution of biosimilars does not come without concerns. Steve Marmaras, manager of state and national advocacy for Global Healthy Living, states, “The frequent description of biosimilars as generic versions of biologics is inaccurate.” He notes that many policymakers at both the state and federal levels operate on the assumption that these drugs are like “Advil” and have generics. But they are not; they are “volatile substances, and have the potential to hurt people” if used incorrectly.

Other critics caution that pharmacists and prescribers will need substantial education on the new products and the proper way to safely dispense them. Many physicians, particularly immunologists and endocrinologists, have significant concerns with immunogenic response. Physicians also feel that it takes away their right to treat patients with the medication they feel is the most appropriate, thereby undermining the physician/patient relationship.

The BPCI Act did not address many issues, and the federal government has yet to establish any official guidelines. Since late 2013, 23 states have considered legislation that establishes standards for substitution of biosimilar products to replace original biologic products. And this writing, however, only eight states have enacted statutes.² While the provisions of the state statutes differ, they do have several things in common:

- FDA must first approve any substitution product as interchangeable for a biological product.
- The prescriber can prevent substitution by stating “dispense as written” or “brand medically necessary.”
- The prescriber must be notified of any allowable substitution made at a pharmacy.
- The patient must be notified that a substitution has been made (and, in some cases, patient consent is required prior to the substitution).
- The pharmacist and physician must retain records of substituted biologic medications.
- The state must maintain a public list of permissible interchangeable products.

With all the discussion about the issue of biologics and biosimilars, there is very little mentioned about how patients view this issue. As the patient advocate for IG Living, I will be following this issue closely and keeping you informed about the approval of biosimilars and how future legislation will impact access to care.

ABBIE CORNETT is the patient advocate for IG Living magazine.

References
**Leslie** Every person responds a little differently to IVIG. Some people see an immediate improvement in strength and numbness with their first course of IVIG; however, others may not have a noticeable improvement until they have completed their second or third course. It is probably worth discussing continuing IVIG with your neurologist to see if he/she believes there is a chance you will see improvement with one or two more courses. After the third course, your neurologist can complete a new neurological assessment and compare it with your baseline exam to determine if you have objective improvement in strength.

**Abbie** I spoke with our specialist, and she advised me that the manufacturer of Gamunex, Grifols, changed its package insert a couple of years ago to remove the requirement to flush with D5W, so this shouldn’t be an issue. None of the immune globulin products are compatible to be co-administered or mixed with saline, but the small volume used for flushing doesn’t cause problems.

**Michelle** SCIG at home is covered at 80 percent by Medicare Part B. The remaining 20 percent is covered by a Medigap supplemental plan. There are no copays or doughnut holes because Part D doesn’t even come into play.

**Question** Will IVIG Improve CIDP Symptoms?

I have chronic inflammatory demyelinating neuropathy, and I had my first round of intravenous immune globulin (IVIG) over a three-day period. The infusion did not provide any improvement in the weakness or neuropathy in my legs and feet. My neurologist is willing to order more rounds of IVIG once a month. I’m wondering if it is worth it. Could I see improvement with additional IVIG?

**Question** Will forgetting to flush an immune globulin IV line with D5W cause a problem?

I have been receiving intravenous infusions of Gamunex for more than two years. Prior to today, my nurse has always flushed the line with DSW. But, I now have a new nurse, and during my last infusion, she forgot to flush with DSW before starting the saline. The packaging instructions state that Gamunex is not compatible with saline and should be separated with DSW. When I inquired about her forgetting, she said, “Oh well, it didn’t cause you any discomfort, did it?” Other than a momentary sensation like a hot flash, it didn’t seem to cause any issues. Should I be concerned?

**Question** Is SCIG covered by Medicare?

I have common variable immunodeficiency, and I would like to switch from intravenous immune globulin (IVIG) to subcutaneous IG (SCIG). However, I am on Medicare and the expense of changing seems prohibitive. I understand that some SCIG manufacturers will provide a subsidy; however, I believe that is only available for lower-income patients. Since Medicare patients like me quickly reach the doughnut hole just from the expense of IG, are there any other options?

**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.

**MICHELLE GREER, RN,** is senior vice president of sales at NuFACTOR Specialty Pharmacy.

**LESLIE J. VAUGHAN, RPh,** is senior vice president of clinical programs at NuFACTOR Specialty Pharmacy.
IMPORTANT SAFETY INFORMATION

Gammaplex® (immune globulin intravenous [human], 5% liquid) is indicated for the replacement therapy in adults with primary humoral immunodeficiency (PI). This includes, but is not limited to, the humoral immune deficit in common variable immunodeficiency, X-linked agammaglobulinemia, congenital agammaglobulinemia, Wiskott-Aldrich syndrome and severe combined immunodeficiencies. Gammaplex is also indicated for the treatment in adults with chronic immune thrombocytopenic purpura (ITP).

Thrombosis may occur with immune globulin products, including Gammaplex. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling central vascular catheters, hyperviscosity and cardiovascular risk factors. Thrombosis may occur in the absence of known risk factors.

Renal dysfunction, acute renal failure, osmotic nephrosis, and death may occur in predisposed patients who receive immune globulin intravenous (IGV) products, including Gammaplex.

Patients predisposed to renal dysfunction include those with any degree of pre-existing renal insufficiency, diabetes mellitus, age greater than 65, volume depletion, sepsis, paraproteinemia, or patients receiving known nephrotoxic drugs. Renal dysfunction and acute renal failure occur more commonly in patients receiving IGV products containing sucrose. Gammaplex does not contain sucrose.

For patients at risk of thrombosis, renal dysfunction or acute renal failure, administer Gammaplex at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

Gammaplex is contraindicated in patients who have had a history of anaphylactic or severe systemic reactions to human immune globulin; an hereditary intolerance to fructose and in infants and neonates for whom sucrose or fructose tolerance has not been established; and IgA deficient patients with antibodies to IgA and a history of hypersensitivity.

Thrombotic events may occur following treatment with immune globulin products, including Gammaplex. Monitor patients with known risk factors for thrombotic events; consider baseline assessment of blood viscosity for those at risk of hyperviscosity.

In patients at risk of developing acute renal failure, monitor renal function, including blood urea nitrogen (BUN), serum creatinine and urine output. Hyperproteinemia, increased serum viscosity, and hyperosmolarity may occur in patients receiving IGV therapy. Aseptic meningitis syndrome (AMS) may occur infrequently with IGV treatment. AMS usually begins within several hours to 2 days following IGV treatment. Discontinuation of IGV treatment has resulted in remission of AMS within several days without sequelae. AMS may occur more frequently in association with high doses (>2 g/kg) and/or rapid infusion of IGV.

Hemolysis and hemolytic anemia can develop subsequent to IGV treatments. Patient risk factors that may be associated with development of hemolysis include high dose (>2 g/kg), non-O blood group, and underlying inflammatory state. Noncardiogenic pulmonary edema may occur in patients following IGV treatment (i.e. transfusion-related acute lung injury (TRALI)). Monitor patients for pulmonary adverse reactions (TRALI). If TRALI is suspected, test product and patient’s serum for anti-neutrophil antibodies.

Gammaplex is made from human plasma and may contain infectious agents, e.g. viruses and, theoretically, the Creutzfeldt-Jakob disease agent. No cases of transmission of viral diseases or CJD have been associated with the use of Gammaplex.

In clinical studies, the most common adverse reactions with Gammaplex were headache, pyrexia, vomiting, fatigue, pain, nausea, hypertension, chills and myalgia.

For more information visit www.gammaplex.com

Please see the Brief Summary of Prescribing Information, including boxed warning, on accompanying page.

REFERENCES

For product information and inquiries, please call (866) 398-0825 or email BPLinfo@LashGroup.com
Primary Humoral Immunodeficiency (PI) - Gammaplex is an Immuneoglobulin E (IgE) preparation for the treatment of adult patients with primary hypogammaglobulinemia (PI) or hypogammaglobulinemia with hereditary intolerance to fructose, also in infants and neonates. It contains human immunoglobulins derived from plasmapheresis of healthy donors who have demonstrated a lack of significant IgE anti-donor antibodies. Patients at risk for anaphylaxis or anaphylactoid reactions should be given a test dose before administration. For patients at risk for anaphylaxis or anaphylactoid reactions, administer Gammaplex at the minimum dose and infusion rate. If signs and symptoms of anaphylaxis develop, stop infusion immediately and monitor for signs of respiratory distress and respiratory arrest. If anaphylaxis or anaphylactoid reactions occur, institute appropriate emergency procedures. Laboratory Tests: To evaluate the transitory rise of the various passively transferred antibodies in the patient's blood may yield positive serological testing results, with the potential for misleading interpretation. These antibodies can be absorbed by erythrocyte antigen e.g. (A, B, and D) may cause a positive test. In individuals with a history of chronic neutropenia, abnormal platelet/immunoglobulin levels, e.g., neutrophils, platelets, and lymphocytes, may be observed in the patient's serum. To avoid potential for misleading interpretation. Passive transmission of the various passively transferred antibodies in the patient's blood may yield positive serological testing results, with the potential for misleading interpretation.
How to Diagnose an Antibody Deficiency,
Summarization Part 3
By Terry O. Harville, MD, PhD

SPECIFIC ANTIBODY DEFICIENCY (SAD) is probably the most difficult of the antibody deficiencies to definitively diagnose. Indeed, some physicians and insurance providers do not recognize it as a disease entity, which can make it difficult for the suffering patient to receive necessary treatment.

In general, the patient with SAD presents with recurrent/chronic respiratory infections (e.g., sinusitis), which may improve with antibiotic therapy, but then recur after antibiotics are discontinued. The initial immune evaluation indicates normal serum IgG and IgM levels and a serum IgA level that may be normal or low. Since approximately one in 500 people has a low serum IgA level without evidence of disease, it is always unclear how to interpret the meaning of this when the serum IgG level is also normal. If evaluated, the patient with SAD will also have a normal blood B lymphocyte count, whereas with common variable immunodeficiency (CVID), the blood B lymphocyte count is expected to be low. The pre-/post-immunization titer response to the pneumococcal vaccine is the most relevant test for antibody deficiency. Subnormal responses ultimately define SAD as an antibody deficiency. Some features of SAD are noted in the Table (contrasted with those of the features of CVID shown in the last column).

In some instances, SAD may evolve into CVID. For example, a patient with serum immunoglobulin levels and a blood B lymphocyte count at the lowest end of the normal range for age may be on the verge of these values further declining, along with worsening pneumococcal titer responses. More elaborate testing of the B lymphocytes may indicate lack of maturation. This could indicate inappropriate B lymphocyte development, which results in subnormal antibody responses, and may also be indicative of further progression toward CVID. For most adults, though, a SAD diagnosis is not typically a transient process that will either progress to CVID or resolve. Re-evaluations over a period of years may yield similar test results consistent with SAD.

The diagnosis of SAD is somewhat more confusing in children. Some children will continue to have the features of SAD into adulthood, therefore further confirming the diagnosis. Some may further progress to CVID. Some may have clinical and laboratory features consistent with a diagnosis of SAD that

<table>
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<tr>
<th>Spectrum of Features of SAD</th>
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<tr>
<td><strong>Normal</strong> (lack of symptoms or features)</td>
</tr>
<tr>
<td>Infection Pattern</td>
</tr>
<tr>
<td>Autoimmunity Pattern</td>
</tr>
<tr>
<td>Serum IgG</td>
</tr>
<tr>
<td>Serum IgA</td>
</tr>
<tr>
<td>Serum IgM</td>
</tr>
<tr>
<td>Pre-/Post-Immunization Pneumococcal Antibody Responses</td>
</tr>
<tr>
<td>Blood B Lymphocyte Patterns</td>
</tr>
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resolve over time. These instances may explain why some discount that SAD exists, since they believe it is a transitory state of illness rather than a specific disease category.

For example, a SAD diagnosis can resolve in young children who have a delay in the maturation of the immune system. Transient hypogammaglobulinemia of infancy (THI) is a condition in which the serum immunoglobulin levels are low (like CVID), but they will improve over time as the child ages. A 5-year-old child who is progressing through the improvement in THI, and being evaluated for recurrent infections, may have developed a serum IgG level in the normal range for age, but have some remaining subnormal pneumococcal responses consistent with SAD. Then, during the next few years, re-evaluations may show pneumococcal responses becoming more fully normal, which means he or she is outgrowing the condition.

Another example is in children who have a delay in the maturation of the antibody responses against polysaccharide antigens (e.g., the ones found in the nonconjugated pneumococcal vaccine), but otherwise have normal-for-age serum immunoglobulin levels. By definition, these children may fit the diagnosis of SAD, but they may outgrow recurrent illnesses. Interestingly, this tends to occur around the time of puberty. Family history may be helpful in these situations because, commonly, these children have a parent or other close relative who was sickly as a child but outgrew the tendency for recurrent illnesses.

A final example of an apparent diagnosis of SAD resolving is due to a viral illness. After a viral illness, especially a more severe illness such as mononucleosis, some individuals may have impaired antibody production (sometimes for years) before making a full recovery. These patients may also fulfill the requirements for a diagnosis of SAD during the time of illness.

Patients with recurrent infections and poor pneumococcal antibody responses (such as with SAD) deserve immune globulin replacement therapy, despite having otherwise normal serum IgG levels.

We will continue this discussion in the next issue. ☑

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.
Reducing SCIG Side Effects

By Michelle Greer, RN

FOR INDIVIDUALS RECEIVING immune globulin (IG) therapy, the subcutaneous (SC) route of administration is often a preferred option. Many people begin SCIG with their first treatment, while others switch to SCIG after a loading dose of intravenous IG (IVIG) or after being treated with IVIG for a period of time. A primary reason for switching from IVIG to SCIG is a reduction in the incidence of systemic side effects that, for some, are intolerable. Examples of systemic side effects with IVIG include headache, nausea and blood pressure fluctuations, as well as more severe adverse reactions such as blood clots and aseptic meningitis.

With SCIG, the most commonly reported side effect is injection site reactions — swelling, redness and/or irritation — that occur at the needle insertion site and are typically localized. These reactions usually resolve within 24 to 48 hours after the infusion is completed. They are more common in the first several infusions, and their incidence normally decreases over time.

While systemic side effects occur with much less frequency with SCIG than with IVIG, in some cases, SCIG site reactions can be severe. In more severe cases, the swelling can be significant, leading to pronounced redness and increased irritation, and even pain. For the first several SCIG infusions, a nurse should train patients on all aspects of SCIG therapy, including a number of techniques discussed here to reduce the magnitude of these reactions.

Needle Size

The gauge (the size of the hole in the needle) and length of the needle can be contributing factors to site reactions. SCIG needles come in 24, 26 and 27 gauges, with 24 being the largest. The larger the number of the gauge, the smaller the needle, so a larger number gauge means a thinner needle being inserted. In some cases, larger gauges are required due to the volume of drug to be administered or if a more viscous drug is required for accurate flow.

There are several layers in the skin. To ensure proper absorption of the IG, the correct needle length must be selected so that, when inserted, the needle tip is in the subcutaneous tissue and the medication is infused therein. If the needle is too short or too long, the medication will not infuse into the subcutaneous tissue, increasing the potential for a more severe reaction.

SCIG needles are available in several lengths. Based on height and weight of the patient, the correct one will be chosen for a patient upon initiation of therapy. Needle length can also be changed at any time if it’s determined inappropriate or if a patient’s weight fluctuates. This is especially important for children as they grow.

Needle Set

The subcutaneous needle is not just a needle alone; it is referred to as a needle set. The set consists of a needle, a backing that sits up against the skin and a short piece of tubing extension that attaches to the longer infusion tubing. In some cases, the material or shape of the backing may contribute to the irritation of the skin. There

Table 1. Subcutaneous Immune Globulin Products

<table>
<thead>
<tr>
<th>Product Name</th>
<th>Manufacturer</th>
<th>Concentration</th>
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<tbody>
<tr>
<td>Hizentra</td>
<td>CSL Behring</td>
<td>20%</td>
</tr>
<tr>
<td>Gamunex–C</td>
<td>Grifols</td>
<td>10%</td>
</tr>
<tr>
<td>Gammagard Liquid</td>
<td>Baxter</td>
<td>10%</td>
</tr>
<tr>
<td>HYQVIA</td>
<td>Baxter</td>
<td>10%</td>
</tr>
<tr>
<td>Gammaked</td>
<td>Kedrion</td>
<td>10%</td>
</tr>
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</table>
are many brands of these sets, so if one isn’t comfortable, there are options.

**Infusion Site**

It is important to choose the proper infusion site. Typical locations for SCIG injections include the abdomen, posterior upper arms and anterior thighs. However, for HYQVIA, the recommended infusion sites are upper to mid abdomen and upper thigh. HYQVIA should not be administered in the arms. Most people who self-administer SCIG do not typically select the upper arms because insertion of the needle requires two hands; however, if someone is assisting them, it is an appropriate site. SCIG should not be administered in the buttocks.

Injection sites should be at least 2 inches from the umbilicus. If multiple sites are required for infusion, the sites should be 2 inches or more apart. The skin over the insertion site should be free from scars, varicose veins, bruising and other types of skin irritation or breakdown. It’s also helpful to not choose the same insertion site over and over (although some believe that using the same site helps reactions dissipate over time).

**Infusion Volume**

The total volume of IG infused in relation to the number of sites is also important. A patient can choose to infuse in only one site or up to six sites. It may be better to infuse in a greater number of sites to reduce the volume infused in each site, which can decrease the chance for irritation.

**Insertion Technique**

Learning how to properly insert a subcutaneous needle, especially if there are multiple sites, is vital to the success of the infusion. The first step is to ensure the skin is properly cleaned. Typically, the site is cleaned with an alcohol wipe. Sufficient time should be given to allow the alcohol to dry before piercing the skin with a needle. When the tubing and needle are primed, meaning the IG is run through the tubing, care should be taken to not let even a drop of IG come through the tip of the needle. The goal is to have a “dry stick,” which means no IG is on the skin and discarded. The sites can typically be left uncovered after removal. However, if there is any bleeding, a gauze or bandage can be applied for a short time.

**SCIG Brand**

There are currently several brands available for SCIG infusion (Table 1). All but one are solely IG solutions, whereas HYQVIA is a combination product. If one brand is causing site reactions and the patient is sure he or she has considered all other sources of irritation, a brand switch may be considered. Any switch should be discussed with the patient’s physician.

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**While systemic side effects occur with much less frequency with SCIG than with IVIG, in some cases, SCIG site reactions can be severe.**

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**Proper Technique Is Key**

SCIG infusions can eliminate the many side effects that often accompany IVIG infusions. However, even with SCIG, reactions can occur. But with training and an understanding of proper techniques, successful SCIG infusions are possible.

**MICHELLE GREER, RN**, is senior vice president of sales for NuFACTOR Specialty Pharmacy.
IN THE NEWS

Education
CIS/USIDNET Host PI Webinar Series

The Clinical Immunology Society (CIS) and the U.S. Immunodeficiency Network (USIDNET) have introduced a new webinar series for clinicians that will emphasize discussion of interesting immune deficiency case presentations. Hosted by the CIS PID Summer School faculty and graduates, the inaugural webinar was held March 31, and included discussions titled an “Overview of Recent Literature” by Joyce Yu, MD, and Kate Sullivan, MD; “Mystery Infections in HXIGM” by Otavio Marques, MSc, and Juliana Lessa Mazzucchelli, MD; and “What’s Up with Too Many Lymphocytes?” by Kiran Patel, MD. For more information on the webinar series, contact CIS at (414) 224-8095 or info@clinimmmsoc.org.

Technology
New Method to Alleviate Shortage of Plasma Therapies

Plasma Tech Biopharmaceuticals has developed a new and innovative method to extract plasma proteins from pooled human plasma samples in an effort to alleviate the potential shortage of available plasma-based therapies. Currently, the Cohn cold fractionation process has been the most common protocol for plasma protein extraction since its inception in the 1940s, with an extraction rate of 7 percent from blood (with plasma concentration of 1.8 grams to 3.5 grams per liter). The new method, called the Optimized Plasma Process, increases the yield tenfold, recovering almost 70 percent of plasma. The technique is expected to be helpful for increasing the availability of plasma therapies to treat immune disorders, autoimmune disease, neuropathies and a host of other diseases currently being researched.

Research
Stewardship Program Improves IVIG Dosing

A study shows that an intravenous immune globulin (IVIG) stewardship program helps ensure guideline compliance for appropriateness of indication and dose. The study, conducted at Brigham and Women’s Hospital (BWH) in Boston, examined a pharmacist-driven stewardship program implemented in 2010 to ensure the hospital was following its own prescribing guideline. IVIG utilization data were collected from January through August 2013 for 194 patients on the indications for IVIG, the number of patients actually receiving the medication, the appropriateness of orders based on indication and dosing adherence, the number of orders discontinued due to guideline nonadherence, and the number of grams dispensed on ideal body weight (the appropriate weight considering the patient’s height, sex and age) as opposed to theoretical grams potentially dispensed based on actual body weight. (Because IVIG does not penetrate into fat, BWH and some other institutions dose based on ideal body weight rather than actual body weight, thereby using smaller amounts of the drug to cut costs.)

The investigators found that 11,706 grams were dispensed; about 2,684 grams of IVIG were averted based on ideal body weight dosing, and 650 grams were averted based on noncompliant indications. Nine IVIG orders were evaluated but denied based on noncompliance with the guideline. On average, about 14 grams were averted per case, resulting in a 19 percent theoretical reduction in the amount of IVIG dispensed. The top indications were hypogammaglobulinemia associated with bone marrow transplantation or oncological disease, idiopathic thrombocytopenic purpura and actual organ rejection.

“The whole concept of antibody stewardship is gaining traction,” said Eric M. Tichy, PharmD, BCPS, a senior clinical specialist in solid organ transplant at Yale-New Haven Hospital in Connecticut. “IVIG is a precious resource, and it’s important that we use it responsibly.”

The study was presented at the American Society of Health-System Pharmacists 2013 Midyear Clinical Meeting.
Research

Gene Therapy Shows Promise for Wiskott-Aldrich Syndrome

A new, small study shows that gene therapy may benefit children and teens with Wiskott-Aldrich syndrome (WAS), a rare immune disorder characterized by low blood platelet count, eczema and recurring infections that is caused by mutations in the WAS gene. In the study, the blood stem cells of seven children and teens with WAS were removed to correct the gene and then injected back into the patients. After being followed for nine to 42 months, one patient died of a preexisting infectious disease, but the six surviving patients had fewer infections, less severe eczema and a decrease in autoimmune symptoms that occur when the immune system mistakenly attacks healthy cells. No severe bleeding episodes occurred after the therapy, and hospitalizations were reduced from roughly 25 days in the two years before treatment to zero in most cases in the two years after treatment.

People with WAS generally die by their 20s and 30s. While blood stem cell transplants from other people can help these patients, they have a high rate of complications. However, because this was such a small study, researchers say they “cannot draw conclusions on long-term outcomes and safety.” Additional trials are needed, along with further follow-up of these patients and participants in a similar study reported on last year.

The study was published in the April 21 issue of the *Journal of the American Medical Association*.


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The Community Pain Center (CPC) is a new website (www.ourcpc.com) that features information, self-management tools and products and services dedicated to improving health and wellness of those directly and indirectly affected by chronic pain. The site was created by Lynne Matallana, founder and past president of the National Fibromyalgia Association (NFA), who has been working with partners and associates to create CPC, as well as two new digital magazines focused on helping people with their chronic pain. Pain AWARE is a quarterly digital publication designed for the chronic pain community at large, and Fibromyalgia AWARE is a quarterly digital magazine that focuses on the unique lifestyle issues associated with fibromyalgia and general wellness.

CPC and its publications include inspirational stories of people overcoming pain, self-management tips, a forum to share personal stories and discuss issues, education of the newest science in treating pain, information on an integrated approach to healthcare, and healthcare reform updates and how they affect people with chronic pain. Also included are product reviews and resources regarding the latest treatments and disease-management tools. A section of CPC is dedicated to healthcare provider education and training, collaboration and connection with the patient community. A major portion of the proceeds from sales and advertising are donated to help support the NFA and other pain-related nonprofit organizations. CPC and its magazines are fully interactive with audio and video components, as well as formatted for mobile readers, tablets and standard computers.

**Resources**

**Chronic Pain Website and Magazines Debut**

Scientists from Gladstone Institutes have discovered a way to prevent the development of multiple sclerosis (MS) in mice using a drug that blocks the production of a certain type of immune cell linked to inflammation and autoimmunity.

There are two types of T cells in the immune system: T helper (TH17) cells activate the immune system, protecting against infections and cancers, while regulatory T cells (Tregs) suppress the system, keeping it in check. In a study published in the *Journal of Experimental Medicine*, researchers discovered that an important regulatory protein, sirtuin 1 (SIRT1), is involved in the production of TH17 cells, and that blocking SIRT1 can protect against the onset of autoimmunity. SIRT1 also has a negative impact on Treg maturation and maintenance, so inhibiting its expression simultaneously enhances the production of Tregs and suppresses the creation of Th17.

In the study, the researchers used a mouse model of MS and treated the animals with a drug that inhibits SIRT1. Typically, MS-model mice experience severe motor problems, eventually leading to paralysis, but when they were given the drug, the mice behaved normally, and they showed no signs of inflammation or cell damage in their spines, classic markers for MS. In contrast with current research, SIRT1 is typically thought of as having anti-inflammatory properties, and compounds that increase SIRT1 — like resveratrol — have been proposed as a way to delay aging. But, first author Hyungwook Lim, PhD, a postdoctoral fellow at Gladstone, says the new research suggests that the protein’s effects are more complicated. “The conventional theory has been that you should activate SIRT1 to improve health and longevity, but we show that this can have negative consequences,” said Dr. Lim. “Instead, we think the role of SIRT1 very much depends on the type of tissue being targeted. For instance, in immune cells, instead of being anti-inflammatory, SIRT1 appears to have a pro-inflammatory role, which makes it a prime target to treat autoimmune disorders.”

The scientists say the next step is to test this strategy using other autoimmune disorders.

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Treating PANDAS

By Rodney P. Lusk, MD

Current treatments for PANDAS have been shown to be relatively effective, but could surgical treatments such as tonsillectomy and adenoidectomy offer more effective results?
PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC disorders associated with streptococcal infections (PANDAS) is a relatively new diagnosis thought to be associated with one in 2,000 children with strep infections. It was originally based on 50 cases reported in 1998 in which 77 percent of children had a preceding group A streptococcal (GAS) infection. In this initial report, PANDAS is characterized with the acute onset of obsessive compulsive disorder (OCD)-type symptoms that include aggressive behavior, compulsive handwashing, compulsive cleaning and frequent checking of locks on doors or windows. Muscular tics are also characteristic, with audible tics noted in some children. Other symptoms that are variably expressed include urinary urgency, hyperactivity, impulsivity, deterioration in handwriting, separation anxiety and decline in school performance. Handwriting deterioration appears to be an early hallmark of the disorder. Anorexia is another psychiatric illness that can be comorbid in PANDAS and has less to do with body image and more with the sensation of texture, taste of food or fear of choking.

A closely related disorder is Sydenham chorea, which is associated with rheumatic fever. PANDAS, however, is not associated with any symptoms of rheumatic fever — specifically fever, arthritis or carditis. And, PANDAS is not considered a “milder form” of Sydenham chorea. Recently, the term pediatric acute-onset neuropsychiatric syndrome (PANS) has been used to describe the acute onset of neuropsychiatric conditions similar to PANDAS but with a broader range of potential etiologies. A key diagnostic feature of PANS is the acute dramatic onset of an obsessive compulsive disorder or severely restricted food intake. Sensory issues are thought to be more common in PANS and can manifest themselves as sensitivity to light, food texture (anorexia), olfactory hallucinations, tactile issues with clothing, shoes and socks, and frequent urge to urinate but without the physiological need. Another classification of similar disorder is called childhood acute neuropsychiatric symptoms (CANS). Each classification has its advocates, and there is certainly significant overlap in symptoms. This article will not focus further on this debate other than to say that there is significant overlap in the symptoms and underlying etiology. Current treatment protocols are similar for all three.

Pathophysiology of PANDAS

It is interesting to note that GAS is not the only infectious agent thought to result in a neurological disease. Mycoplasma pneumonia is implicated in Tourette syndrome, with 59 percent of Tourette syndrome patients having elevated antibody titers. Lyme disease is also thought to be a trigger for PANS, with OCD symptoms being prominent. And, there is a large body of knowledge indicating that Toxoplasma gondii, from infected cat feces, may be associated with schizophrenia. The mechanisms of these infectious processes with the neurological system is likely varied, but as we learn more, a common immunological pathway may be implicated.

The underlying pathophysiology of PANDAS is important when considering possible treatment modalities. The pathophysiology of PANDAS is thought to be based on molecular mimicry of GAS antibodies that target brain proteins leading to the clinical manifestations of PANDAS. GAS antibodies may directly stimulate or block receptors of the basal ganglia (a region of the base of the brain that is responsible for involuntary movements), or affect immune complexes that lead to inflammation of the basal ganglia. PANDAS children have also been found to have significantly higher levels of antibodies that trigger calcium-calmodulin–dependent protein kinase II (CaM kinase II) production. These cross-reactive antibodies may interfere with neuronal signals by increasing CaM kinase II production in the basal ganglia, eventually leading to dopamine dysregulation. This dysregulation may subsequently lead to the clinical presentation characteristic of PANDAS. Animal models are being developed to further define the underlying pathophysiology of this disorder.

The underlying pathophysiology of PANDAS is important when considering possible treatment modalities.

PANDAS Diagnosis

Definitive laboratory tests for the diagnosis of PANDAS are lacking; however, certain tests are useful. Identifying strep through cultures is important. As many as 85 percent of patients are positive with one serology test, and 95 percent are positive when multiple tests such as ASO and anti-DNase B titers are used. These two tests are clinically useful and routinely obtained.
Antibodies to human brain enolase (AE), neural tissue and anti-streptococcal antibodies have been shown to be significantly elevated in patients with the early onset of psychiatric disorders. The use of neuroimaging (MRI) has been used, but it is nonspecific. An MRI most commonly shows inflammation and enlargement of the basal ganglion. With progressive decrease in antineuronal antibody titers, the inflammation in the basal ganglion has been shown to progressively decrease.

**Since streptococcal infections are associated with PANDAS, prompt antibiotic intervention remains the primary course of medical management, especially in the acute phase.**

**Current PANDAS Treatment**

Since streptococcal infections are associated with PANDAS, prompt antibiotic intervention remains the primary course of medical management, especially in the acute phase. The primary antibiotics include penicillins (amoxicillin or amoxicillin plus clavulanic acid) or cephalosporins. Other forms of medical management include sporadic reports of successful management with steroids and nonsteroidal anti-inflammatory drugs, which are thought to reduce inflammation of neurological tissue, especially in the basal ganglion. The effects of these mostly appear in case reports, and no general conclusions regarding their effectiveness can be provided.

Two other forms of management, immunotherapy and therapeutic plasma exchange (TPE), have been shown to be somewhat encouraging in small case series. Immunotherapy is based on providing a large number of intravenous immune globulin (IVIG) antibodies pooled from adult blood donors. It is thought that providing a large number of antibodies against bacteria and viruses will result in a greater ability to fight the infection. However, this treatment is not without significant side effects, which include chills, low-grade fever and headache, and rare serious side effects such as difficulty breathing, chest pain, seizures and severe anaphylactic reactions.

TPE is a process by which whole blood is removed from the patient, the plasma is removed from the blood, and then the red blood cells are returned to the patient. TPE is thought to exert benefits by removing autoantibodies and antigen-antibody complexes, which potentially reduces the inflammation. The method seems to be the direct opposite of immunotherapy. The treatment is often provided in an inpatient setting, and requires either a central or femoral catheter. It is also associated with adverse effects that are frequent and can be serious.

While both immunotherapy and TPE have been shown to be effective, they are expensive and require hospitalization. Therefore, it would be advantageous if less expensive therapies with fewer possible adverse effects could be found.

**Treating PANDAS with Tonsillectomy and Adenoidectomy**

Because of the presumed infectiousness of strep, it would seem logical to remove tissue that is a likely source of strep infections, namely the tonsils and adenoids, as a possible PANDAS treatment. However, reports in the literature have been mixed. Early case reports were encouraging, showing improvement and, in some cases, resolution of symptoms. These were all case or small series reports, so it is difficult to know the true role of tonsillectomy and adenoidectomy.

Recently, a study of 114 patients with PANDAS was conducted to determine whether tonsillectomy and/or adenoidectomy might improve a child’s neuropsychiatric course. Patients were divided into two groups: those who had surgery and those who didn’t. The researchers found that, because ASO titers (a blood test to measure antibodies against streptolysin O) were not different between the two groups, tonsillectomy and/or adenoidectomy does not prevent PANDAS. They also found that surgery did not result in reduced OCD or tic severity compared with the non-surgery group. In addition, the researchers noted that the symptoms of PANDAS were not different between the two groups. There are, however, problems with this study. First, it had only 20 patients who had previous surgery and subsequently developed PANDAS. Second, tonsillectomy and adenoidectomy were lumped together. This is a problem because both tissues need to be surgically addressed. The researchers acknowledge shortcomings in their study. The patients who had
tonsillectomies and/or adenoidectomies had the procedure prior to onset of their neuropsychiatric disorders. None of the patients had their procedure during or shortly after the acute onset of their symptoms. Further, the researchers acknowledged that: “All of our subjects had existing OCD and/or tics at study entry. If a subset of youth did have OCD/tic remission after the surgical procedure, our study would not have detected those.” Therefore, the question remains: Does tonsillectomy and/or adenoidectomy have a role in the treatment of PANDAS during the first few months or years of the onset of neuropsychiatric symptoms?

Similarly, a multi-institutional study in Italy showed that tonsillectomy had no effect on the symptomatology, progression, streptococcal and neuronal antibody titers, or the clinical severity of neuropsychiatric symptoms in children with PANDAS. The researchers concluded that the clinical progression, antibody production and neuropsychiatric symptom severity did not differ with surgical intervention.

Contrary to these results is unpublished data (with a manuscript in review) that shows tonsillectomy and adenoidectomy in children with symptoms of PANDAS. We examined 12 children with PANDAS/PANS who underwent tonsillectomy and adenoidectomy (one out of the 12 had adenoidectomy alone) during a relatively acute phase of their disease. The majority of parents kept a daily symptoms diary before and after surgical intervention. There was significant improvement in symptoms (tics, OCD, anxiety, regressive behavior) in nine of the 12 children who had surgery. Of the nine who were improved, three reported excellent results, were symptom-free and off all medications. The remaining six were markedly improved but still required intermittent antibiotics during upper respiratory tract infections. The three who did not improve were treated with IVIG. One markedly improved and is symptom-free, another is improved but has relapses and the third continues with symptoms and has ongoing IVIG treatments with ongoing symptoms.

We concluded that tonsillectomy and adenoidectomy appear to have remarkable improvement (resolution) in some children, improvement with intermittent relapses in others and no significant improvement in about a quarter of the patients. The cause of the variable responses is unclear, but it could be secondary to genetic predisposition or duration of symptoms. Admittedly, these numbers are very small. But as a pilot study, the results indicate that tonsillectomy and adenoidectomy in the relatively acute phase of disease warrant further study. At this time, however, we would not recommend routine tonsillectomy and adenoidectomy in children with PANDAS/PANS.

These results are supported by other reports in the literature. One multi-institutional study compared nine patients who were treated with tonsillectomy with 10 patients treated with antibiotics. Four of the nine patients had complete resolution of their symptoms after tonsillectomy. The researchers concluded that PANDAS patients who did not respond to antibiotics may have significant benefit from tonsillectomy. There are several other case reports showing resolution of symptoms after tonsillectomy.

If antibody complexes indeed cause inflammation of neural tissue, it would seem that the greater intensity and duration of inflammation, the greater the damage to the neural tissue. This, in turn, may be associated with less responsiveness to any therapeutic intervention. As such, it’s possible that tonsillectomy and adenoidectomy are less effective in children with longer duration of symptoms.

Better Studies Are Needed

Investigations to date of successfully treating and resolving PANDAS are woefully inadequate of good prospective data that take into account accurate diagnosis and duration of symptoms. This important data can be gathered only through routine, even daily, assessment of patient symptoms to and after any intervention, either medical or surgical. And, adequate numbers for investigation can only be accomplished through a multi-institutional study with data acquired through a central database repository. It is hoped that continued and more accurate and thorough research will find better treatments for this puzzling disorder.

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References

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Exercising
While Living with Neuropathy

By Matthew D. Hansen, DPT, MPT, BSPTS

Those who suffer from neuropathy can maintain and improve their physical strength, as well as reduce nerve pain, with a variety of basic exercises.
IT’S ESTIMATED THAT more than 20 million Americans suffer from peripheral neuropathy, a disorder of the nerves that run between the spinal cord and the body’s skin (sensory and autonomic nerves), muscles (motor and sensory nerves) and internal organs (autonomic and sensory nerves). Approximately 30 percent of peripheral neuropathies are of unknown cause, and another 30 percent are related to diabetes. Other contributing factors may be autoimmune disorders, endocrinologic or metabolic disorders, nutritional imbalances, nerve entrapment/compression, certain medications, tumors and heredity.

Autoimmune diseases that may affect the peripheral nerves and/or their connection with muscles include chronic inflammatory demyelinating polyneuropathy, lupus, Sjögren’s syndrome, rheumatoid arthritis, POEMS syndrome, Guillain-Barré syndrome and its variant axonal or neuronal neuropathy, Lambert-Eaton syndrome, myasthenia gravis and multifocal motor neuropathy. In some cases, it’s not uncommon for peripheral neuropathies and autoimmune disorders to occur concurrently, but they may be unrelated.

Diagnosing neuropathies early is one way to control the disease. But, once developed, exercise can help. Following are a brief discussion of the signs of neuropathy and some basic exercises to help control its symptoms.

Symptoms of Peripheral Neuropathy

The earlier peripheral neuropathy can be identified, the better the chances are of controlling it and preventing permanent damage. The unpredictability of peripheral neuropathy’s course may make it even more trying, with symptoms that may progress over years, come on rapidly or come and go.

Sensory nerves, which run throughout the body, are the nerves most frequently affected, often in both hands and feet. Someone with neuropathy of the sensory nerves may experience pain (frequently described as burning or stabbing), tingling, numbness and/or other unusual sensations in the distribution of the nerves. Secondary complications may include poor balance or development of wounds (e.g., pressure sores on the feet) from harmful stimuli that can’t be felt, sometimes as innocent as a pebble in the shoe.

When motor nerves are involved, the most common symptom is weakness that further complicates balance, mobility and other activities of daily life. Other symptoms may include muscle cramping, fasciculations (i.e., twitching), decreased reflexes and atrophy (muscle shrinkage).

Autonomic nerves work unconsiously to control the function of the body’s internal organs. Depending on which nerves are involved, autonomic neuropathy may affect heart rate, blood pressure, digestion, bowel and bladder control, and the ability to sweat.

Benefits of Exercise for Neuropathy

Although exercise may not be able to fully reverse the symptoms of peripheral neuropathy, it can help to preserve or improve muscle strength, balance, range of motion and circulation (which increases oxygenation and the associated healing of nerve tissue). According to Greg Carter, MD, professor of rehabilitation medicine at the University of Washington, aerobic exercise “improves not only physical functioning but helps fight depression, maintain ideal body weight, and improve pain tolerance.”

Unfortunately, there aren’t many scientific studies related directly to the effects of exercise on autoimmune disease-related peripheral neuropathies. However, there are studies regarding exercise’s effects on diabetic peripheral neuropathies (though care must be taken not to draw exact comparisons). Some of these studies have actually demonstrated significant decreases in pain and other symptoms, as well as an increase in innervation of the nerves that run to and from the skin.

The earlier peripheral neuropathy can be identified, the better the chances are of controlling it and preventing permanent damage.
T.K.’s Story

While exercise can be beneficial for neuropathy, it can also pose a threat. Following is a first-person account from “T.K.” of the dangers exercise can pose for neuropathy patients if not performed correctly:

“In 2005, pain in my hands and feet led to a diagnosis of diabetes and diabetic neuropathy. Brisk walking on my treadmill (30 to 35 miles a week) brought me back to my high school weight [and an improved blood glucose score]. However, because of my neuropathy, brisk walking became too hard on my feet, causing blisters and temporary numbness in my toes despite my best efforts. At the suggestion of one of my doctors in 2013, I purchased an exercise machine to help control my blood sugar. Unfortunately, I used the machine incorrectly.

“By February 2014, the outer halves of my big toes were numb. I did not realize it was a warning sign and could morph into greater neuropathic pain. Thinking the numbness meant the nerves were dead and I could do no further damage, I maintained my workouts. In September 2014, my big toes and balls of my feet suddenly became hypersensitive to pressure, and the simple act of walking brought increased burning, pain, electric shocks and stabbing sensations, especially in the big toes and balls of my feet. The neuropathic pains from the wrong exercises plagued and continue to plague my every step. I can no longer use the exercise machine, have difficulty walking and spend most of my time on my side in bed. When I walk, it is on my heels and the sides of my feet. I purchased seven Cashier mats for our wood floors and stand on folded towels in the shower. I am waiting on a quad cane in hopes it will reduce the weight on my feet when I walk.”

Safety

When the feet are affected by neuropathy, exercises should always begin and end with a foot check to ensure the absence of pressure sores or blisters. Wearing socks that are designed to absorb moisture and reduce friction can help to provide protection. Supportive shoes and orthopedic inserts to cushion the feet may also assist in preventing injury and increased pain that can result from weight-bearing activity.

High-impact exercises such as aerobics, jumping or running (especially on a treadmill) should be avoided. These types of exercises not only pound the feet, but they can also be very unforgiving if someone missteps. Special consideration should be given to activities that don’t place someone with neuropathy at unnecessary danger of falls.

A proper exercise program can improve balance. However, those who experience neuropathy in their upper extremities should take care not to overstretched the shoulders and wrists. When performing resistive exercise, a neutral wrist position should be maintained, possibly with the use of weightlifting gloves, and weight should be added slowly because of the possibility of exacerbating “entrapment neuropathies” such as carpal tunnel syndrome.

Stretching Exercises

Any exercise session should start with a warm-up. Slow, sustained stretching (at least 30 seconds per stretch; repeated three to five times) can help to avoid muscle cramping, maintain or increase flexibility, and improve blood circulation along with oxygen delivery, which can lead to healing or regeneration of peripheral nerves and help to avoid soreness. Yoga and tai chi are other good activities to help increase flexibility. Following are some specific stretching exercises:

Calf stretch. Stand on a bottom step, hold onto the rail and let your heels hang off the edge to stretch the calf muscles and Achilles’ tendon (Figure 1). If pain increases, or if you have a difficult time maintaining balance, you can perform the same stretch while sitting, extending your leg(s) and using a towel around the ball of the feet to pull the ankle toward you (Figure 2). When the stretch is performed with a bent knee, it will target the Achilles closer to the ankle; when it is performed with a straight knee, it will target higher up the leg, closer to the knee and hamstrings.

Hamstring/sciatic nerve stretch. There are a number of ways to stretch the hamstring muscles, which make up the bulk of the back of the thigh. Perhaps the simplest method is to sit on a chair or sofa and extend one
leg out in front of the body, and then lean forward at the waist until a gentle stretch is felt (Figure 3). The stretch can be increased in the hamstrings, as well as target the long sciatic nerve that runs down the back of the leg, by reaching toward the foot with the opposite hand, pulling the ankle and toes toward the body and/or slowly bending the head and neck forward.

**Figure 3. Hamstring/Sciatic Nerve Stretch**

*Prayer stretch.* Not to be confused with the back stretch by the same name, the prayer stretch increases the pliability and blood flow to the median nerve that runs from the shoulder, down the arm and across the wrist. The median nerve is often involved in upper extremity neuropathies, including carpal tunnel syndrome. Press the palms together in front of the chest in a prayer position and slowly raise the elbows and lower the hands while still keeping them pressed together (Figure 4). Hold the position once a moderate stretch is felt, but ease up or discontinue the activity if tingling or numbness returns.

**Partial-Weight-Bearing Exercises**

Partial-weight-bearing activities are performed in a position or medium (e.g., water) that allows part of the body’s weight to be transferred to the feet but not all of it. Biking (especially recumbent biking), water aerobics and wading in a pool are great partial-weight-bearing activities. The buoyancy principles of water can be particularly beneficial because the body’s weight is only roughly 50 percent of normal when a person stands in water up to hip/waist level and just 10 percent of normal when a person stands in water that is up to his or her chest.

**Non-Weight-Bearing Exercises**

If any degree of weight-bearing is a cause for increased pain, non-weight-bearing (a.k.a., open chain range-of-motion) or isometric exercises can also be performed.

Range-of-motion exercises (similar to stretching but without the hold) help to improve circulation and stimulate nerve conduction. Begin the routine by sitting in a chair and performing 10 to 20 ankle pumps on each side; then perform the same number of foot circles, first clockwise, then counterclockwise (Figure 5). You can slightly increase weight-bearing through the feet by performing toe and heel taps: Lift your toes as high as you can, then tap them against the floor as you lift the heels; perform the opposite motion by tapping the heels and lifting the toes. Then, move up to the knee joint by lifting one of your feet into the air with an extended knee, lowering it to the floor and repeating 10 to 20 times on each side.

**Figure 4. Prayer Stretch**

Open chain range-of-motion exercises can be repeated in the fingers, wrists and elbows by following the same pattern. Open and close the fingers and hands; alternately bend the wrists up, then down; and bend and straighten the elbows. Range-of-motion of the hips and shoulders can also be performed, but is not described here because the two joints represent more than a dozen motions, and most neuropathy symptoms are experienced in the distal limbs, farther away from the trunk of the body (i.e., the hands and feet). For a more detailed description of non-weight-bearing activities, a physical therapist, personal trainer or well-designed home exercise video can be of assistance.

To perform isometric exercises, contract the targeted muscle, hold the contraction for three to five seconds, relax and repeat.

**Balance**

It’s always a good idea to place at least one hand on a stable structure (e.g., a countertop, stair rail, table or steady chair) when practicing balance activities. As a given activity becomes easier to perform, dependence on upper-extremity support can
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Limitation of Use: Safety and efficacy of chronic use of recombinant human hyaluronidase in HYQVIA have not been established in conditions other than PI.

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- 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.

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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 Baxter and co-manages working with Baxter 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 Baxter immediately by contacting the MyIQSource Patient Support Program.

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

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 the 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 Baxter Healthcare Corporation 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.

Baxter and Hyqvia are trademarks of Baxter International Inc.
June 2015 USBS/MIS/14-01631(1)
More free time with HYQVIA\(^1\)

Infusing 1 time a month with HYQVIA doesn’t mean your infusions will take longer. Typically, infusions take less than 3 hours with HYQVIA [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase]. Instead, you’ll have more free time.

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.

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 Baxter 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.
decrease until just one or two fingers are in contact with the supportive object.

1) Begin by doing simple weight shifts. With the feet spread shoulder width apart, shift all of your weight to the right leg and slowly come up on the toes on the left. Now shift your weight back to the left leg and slowly come up on the toes on the right.

2) After performing several repetitions of weight shifts, slowly rise up on your tiptoes, then rock back on your heels.

3) Now, march in place by alternately lifting just your heels off the floor. As the activity becomes easier and remains nonpainful, progress to lifting the feet higher and higher off the floor.

4) Finally, side-step around the kitchen counter in one direction and then the other, by leading with one foot, then bringing the opposite foot next to it. As balance improves, you can take larger steps.

The Right Kind of Exercise Is Key

The exercises presented in this article can be used as a starting point or as a routine to revert to when the neuropathy is aggravated. When it is, foot or hand braces may help to reduce symptoms during regular daily activity, and can be removed to perform non-weight-bearing range-of-motion exercises. If these activities can be performed easily and pain-free, safely experiment with more weight-bearing activities that don’t increase fall risk.

T.K.’s purpose in sharing his story was to inform and warn neuropathy patients and healthcare professionals who treat them of the dangers of over-exercising and/or of performing the wrong kind of exercise due to a tendency to exacerbate neuropathic pain: “Increased pain in exercise and numbness for neuropathy patients are signs that something is wrong and must be investigated. The irony is that I unknowingly caused compression/trauma-induced neuropathic pain while trying to control my blood sugar! Exercise is good, but the wrong type and kind for a neuropathy patient with damaged nerves is dangerous…. If I can prevent just one person from inadvertently causing severe neuropathic pain or more damage to damaged nerves by spreading the word about hazards of the wrong type and kind of exercise, perhaps some good can come from my misfortune.”

Keep in mind that when it comes to neuropathy, it’s all about taking one step at a time.

MATTHEW D. HANSEN, DPT, MPT, BSPTS, is a practicing physical therapist in Utah and president of an allied healthcare staffing and consulting agency named SOMA Health, LLC. He completed his formal education at the University of Utah, Salt Lake City, and has additional training in exercise and sports science, motor development and neurological and pediatric physical therapy.

References

Author’s note: Specially designed home exercise videos can be purchased at www.freedom2move.org or www.sitandbefit.org.
According to recent statistics, 133 million Americans (or 45 percent of the population) have at least one chronic disease. By 2025, it is estimated that chronic diseases will affect an estimated 164 million Americans — nearly half the population. And as anyone living with a chronic illness can attest, the cost of care can be astronomical, yet many patients have minimal understanding when it comes to proper estate and financial planning.

Martin Shenkman, a New Jersey CPA and attorney who lectures on estate planning for the chronically ill, says that most people have no idea where to start when it comes to estate planning, and the unexpected burden of chronic illness only increases the complexity of it. Shenkman learned firsthand what a daunting prospect it can be when his wife was diagnosed with multiple sclerosis in 2006. After making adjustments to his life insurance holdings, trusts and other financial planning tools, he made it his mission to educate the public and financial professionals about the importance of customizing planning documents for people with a chronic illness. “You must address the issues at hand and then tailor them to the current situation you are in,” he explains. “You also must have a plan prepared to deal with the many legal and financial situations your family members will likely deal with in the event of your death.”

His website, laweasy.com, offers the following additional tips:

- Designate a power of attorney, but be very cautious about who this person is.
- If your life timeline has been shortened tremendously, re-evaluate your portfolio and investment strategy.
- Consider setting up a living trust.

Begin with a Budget

Many financial considerations impact short-term and long-term quality of life. Obviously, everyone’s situation is unique, but there are general recommended financial guidelines that can help to build financial security, and it all begins with establishing a
realistic budget. A budget is a useful financial tool for anyone, but it’s especially valuable for those with a chronic illness because it serves as a foundation for all other financial decisions. Both income and expenses may change if an individual is unable to work or if medical costs rise, and it’s highly likely there will be unexpected medical costs related to the chronic condition.

Prior to crunching numbers, the first task, although unpleasant, involves learning as much as possible about the likely progression and symptoms of the illness so that informed decisions can be made. For example, home healthcare might be required at some point. If a wheelchair will be needed, money may be required to widen doorways or to make additional home modifications. Retirement may come earlier than planned, or a spouse may need to leave work to be the caregiver. Knowing this information, a financial adviser can adjust an individual’s investment portfolio and budget to prepare for projected costs. An estate planning lawyer can revise the power of attorney and healthcare directives to address specific potential disabilities related to illness.

Cyndi Hutchins, director of financial gerontology at Bank of America Merrill Lynch, suggests setting up separate reserves to pay for future healthcare expenses such as shifting assets toward income investments like bonds. Another possibility is setting up a deferred annuity that could kick in down the road when living expenses related to illness are expected to rise. “These types of investments allow you to turn on the income stream when you need it,” she says.³

Keeping good records is also important. For example, it is a good idea to set up a system to help track medical expenses and insurance claims. And, a list of instructions that includes where to find important household and financial information can be prepared for a trusted friend or relative who can access it in an emergency.

Another step to consider is streamlining finances by consolidating various accounts. Having everything in one place can make it easier and quicker for an individual or a trusted advisor to manage. One time-saving step is to set up automatic bill payment or online banking. This will not only save time each month, it will also help to track expenses and see where all the money goes.

The Art of Cutting Costs

Many chronic illnesses require expensive medicines. Financial experts advise those on Medicare to review the Part D prescription drug or Advantage plan after diagnosis to see if it would be advantageous to make adjustments to health plans. If Medicare isn’t an option, an insurance broker can help find a plan that covers much of the drug costs. When it comes to healthcare exchanges, individuals should be sure to do their homework. A study by HealthPocket.com⁴ found that average out-of-pocket costs for patients taking one of five common specialty drugs were lowest for platinum plans, even though those plans charge higher premiums than gold, silver and bronze plans.

Some foundations, states and drug companies offer programs that pay for out-of-pocket costs insurance doesn’t cover. If an individual qualifies, he or she can get discounts, help with co-payments or several months of free prescriptions. Some programs require proof of financial need, while others don’t. “It all depends on the drug, the company and the condition,” says Tricia Blazier, personal financial planning manager at Allsup, a firm that helps people get disability and healthcare benefits.³ Links to programs can be found at the Partnership for Prescription Assistance (www.pparx.org) and at RxAssist (www.rxassist.org). Specific disease organizations may also offer financial help.

The Ins and Outs of Insurance

Understanding insurance coverage and making sure the right kind is purchased is essential. A study by Prudential Insurance titled “The 5 Ws of Chronic Illness Care”⁵ explores important steps individuals can take to mitigate the financial impact of a chronic illness, with an emphasis on having the correct insurance products and coverage in place. According to the study, some considerations to keep in mind include:

- Cost: How much will the product cost? Is it a one-time payment or are payments ongoing? Are the costs fixed or can they increase? If the cost is affordable now, will it still be in retirement, when income is more likely to be fixed?
- Access: How easily and quickly can funds be accessed?
- Payment flexibility: Does the product provide payments in the form of reimbursements for only qualified medical expenses, or does it provide funds that can be used for any expenses once the requirements have been met?
- Duration and continuity: How long will insurance coverage last — for a lifetime or for a set time period? Is there a limit to how long an individual can use it once payments begin? How long will the payments last once they have begun? Can payments be started and stopped while coverage is maintained?
- Amount: Is the coverage based on a set amount or time period? What happens if the amount isn’t enough for an illness?
- Prioritizing and adding layers of protection: Just as there is no one product that perfectly addresses all the issues of chronic illness care costs, there probably isn’t one product on the market that is perfect for each person. Therefore, a product should be chosen based on priorities, and more than one layer of coverage may help address all priorities, although this approach can be more costly.

Types of insurance to consider depend on specific circumstances,
but most financial planners agree that if an individual owns term life insurance, he or she may want to consider converting it to permanent life insurance to provide protection for loved ones. And, depending on what type of permanent life insurance it is, benefits may be accessed today for expenses down the line. For example, New York Life recently introduced a chronic care rider that is available on whole life and custom whole life policies purchased after Jan. 10, 2014. The rider provides an opportunity for the policy owner to receive a portion of the policy’s face amount should the insured become chronically ill.

For those who already own a life insurance policy that accumulates cash value, it can be borrowed against. If the policy has an accelerated benefits rider, a certain percentage of the death benefit can be unlocked to use while the insured is still living. Individuals who are caring for a loved one with a chronic illness will want to make sure their own life insurance is in place and sufficient to support the person they are caring for, in case they pass away unexpectedly.

There is also the catch-22 of affording life insurance with a pre-existing condition. According to Bankrate.com, while it has historically been true that it is next to impossible for those with pre-existing conditions to find affordable insurance products, the insurance landscape has shifted dramatically in recent years, making it easier, though not inexpensive.6 “Better detection, earlier diagnosis and more effective treatment of illness mean today’s patients live longer, healthier lives,” notes Dr. Valerie R. Kaufman, vice president and chief medical director at MassMutual. “Insurance companies are offering [life] insurance to those with chronic medical conditions because there is much more medical information available.”

While the outlook is more optimistic now, there are, of course, no guarantees, and the ability to purchase a plan will be determined by many factors, including:

• Specific type of illness
• Severity of the illness
• Time elapsed since diagnosis
• Stability of the applicant’s health
• Treatment regimen

Disability insurance is another key component of the financial plan. A typical group plan offered by an employer will replace up to 60 percent of an individual’s salary, but a supplemental plan or an individual policy will cover up to 80 percent. An insurance advisor can perform a risk-management audit to determine how much coverage is needed.

It’s a good idea to consult with an impaired-risk specialist when shopping for insurance. This insurance agent knows which life insurance companies offer the most competitive prices for applicants with pre-existing health conditions. Having an advocate who can do the legwork can be well worth the time and effort.

The Essentials of Estate Planning

Estate planning is possibly one of the most important components of a solid financial plan. Not only is it important to “get your affairs in order” in the event of death, but there are many estate planning tools to help manage finances while living.

For example, a durable power of attorney can help protect property in the event an individual becomes unable to handle financial matters. It also allows that person to authorize someone else to act on his or her behalf to do things like pay everyday expenses, collect benefits, watch over investments and file taxes.

A living trust (also known as a revocable trust) is a separate legal entity that protects property and investments. It’s called a living trust because it’s meant to function while a person is alive. Thus, the trust is controlled by the person who creates it, who can change the trust terms, transfer property in and out of the trust or end the trust altogether. That individual can also name a co-trustee such as a financial institution or a loved one to manage the assets in case he or she is unable to do so.

An advanced medical directive lets others know what medical treatment is desired, and it establishes who will make medical decisions for that individual in the event he or she can’t express preferences. Depending on what’s allowed by the state in which the person lives, this document may include a living will, a durable power of attorney for healthcare, and a do-not-resuscitate order.

Getting Affairs in Order

It’s a well-known adage that if you fail to plan you plan to fail. Taking the time to get financial affairs in order now can ease anxiety about the unknown, and help create financial security no matter what the future may hold.

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.

References
sheet_81009.pdf.
five-essential-planning-tips-for-chronic-illnesses.
MUCH OF TODAY’S modern diagnostic process is heavily reliant on the interpretation of laboratory studies, especially in the areas of primary immunodeficiency disease (PI) and autoimmune disorders. However, the interpretation of even the most common lab tests is often not fully explained to patients, leaving them misinformed about such a routine, and some would argue essential, part of their healthcare management.

This article focuses on two of the most common routine lab tests — the complete blood count (CBC) and the basic metabolic panel (BMP) — that most patients have received or will receive at some point in their care. The purpose of these routine screening labs is not to provide a specific disease diagnosis. Rather, the purpose is to help physicians develop a panoramic portrait of their patients’ health by examining the function of some of the most essential organ systems in their bodies. The CBC details the status of patients’ blood cells. Irregularities may indicate problems with the immune system, bone marrow disease, drug toxicity, nutritional deficiencies, signs of infection and other organ dysfunctions. The BMP evaluates the levels of the most abundant chemicals in the blood such as sodium, potassium, chloride, bicarbonate and glucose. Abnormalities may indicate problems with kidney function, diabetes and side effects from medications.

**CBC**

In the CBC, the most important elements are hemoglobin, white blood cell count and platelet count (see Table 1). Hemoglobin is the molecule in red blood cells that carries oxygen. The measurement of hemoglobin in the blood is a direct measurement of oxygen-carrying capacity and an indirect measurement of the abundance of red blood cells. The normal range of hemoglobin is between 13 and 17 grams per deciliter for men and between 12 and 15 grams per deciliter for women.

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<th>Table 1. Normal Ranges for Key CBC Values</th>
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<tr>
<td>White Blood Cells</td>
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<td>Hemoglobin</td>
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<td>Platelets</td>
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altitudes. The concern for polycythemia is that the increased concentration of red blood cells may lead to thickening of the blood, which increases the risk of clot formation in the vessels.

White blood cell count is often the first element listed in the CBC. White cells are essentially all blood cells other than red cells, so it is a heterogeneous mix, including neutrophils, lymphocytes, eosinophils, basophils and macrophages. The normal range of white count is between 4,500 and 10,000 cells per microliter. An elevated total white count is often a sign of increased systemic inflammation and possibly infection. Neutrophils and macrophages are often elevated if there is a bacterial illness. Eosinophils are typically elevated in allergic disease, but they can be elevated in some forms of autoimmune disorders, as well as hematologic conditions. A low white count can be indicative of immunodeficiency due to an inadequate number of immunologic cells. A decrease in a specific type of immunologic cell can help point toward a specific form of immunodeficiency (i.e., innate vs. adaptive immune system defect). Decreased white count may also indicate a decreased ability to fight off infections.

The last major component of the CBC is the platelet count. The normal platelet count is generally between 150,000 and 400,000 per microliter. Platelets are the crucial elements in blood that help it clot. A platelet count below normal could indicate that the blood may not clot as efficiently and bleeding time would increase. A low platelet count could be secondary to a number of causes, including increased destruction of platelets (due to drugs or autoimmune disorders), increased consumption of platelets (due to aggregation in small vessels that causes them to be used up, thus decreasing the circulating concentration) or decreased production of platelets (due to bone marrow or liver abnormality). Certain PIs such as Wiskott-Aldrich syndrome are associated with low platelet counts. Common variable immunodeficiency is also often associated with autoimmune platelet destruction, and sometimes the first presenting symptom is a low platelet count. An increased platelet count can occur as an isolated disorder due to abnormal increase in production within the bone marrow. Again, just like in polycythemia, the concern is that an overly high level may increase the blood’s propensity to cause abnormal clotting in the vessels, leading to blockage. Platelet count can also often be increased when there is inflammation, which may guide the physician toward discovering an underlying infection or autoimmune condition.

BMP

The BMP is an overview of the concentration of key chemicals in the blood that help the body function. There are several elements of the BMP, but the most important ones are sodium, potassium, bicarbonate, glucose and creatinine (see Table 2). Sodium is one of the most abundant molecules in the blood, and abnormalities can provide insight into the potential for metabolic disorders. A normal sodium level can vary among individuals, but it generally runs between 135 and 145 mmol per liter. A sodium level above the normal range can be indicative of dehydration from inability to obtain water, an imbalance of hormones that are involved in sodium excretion/retention, loss of water (from diarrhea or medications that lead to water loss) and kidney disease. A sodium level below the normal range can indicate an imbalance of the hormones that are involved in sodium excretion/retention, loss of sodium through the urine or the gastrointestinal tract, heart failure, liver failure or kidney failure. In addition, an abnormally low sodium level can be a reflection of inadequate diet or massively excessive water consumption. Mild to moderately low sodium levels are often asymptomatic, but a severely low level can result in changes in mental activity, as well as seizures.

Potassium is highly concentrated within the cells of the body, and only a small amount circulates in the blood, but it is very tightly regulated. The normal range of potassium in the serum is generally between 3.5 and 5 milliequivalents per liter. A low potassium level is usually secondary to either loss through the gastrointestinal tract or kidney or a temporary shift of potassium from the bloodstream into the cells. Certain medications may also lead to increased excretion of potassium by the kidneys. Often, mildly decreased potassium is asymptomatic, but a significantly low level can present with nausea, vomiting, weakness, muscle cramps and cardiac arrhythmia. A high potassium level can be caused by a shift of potassium out of the cells

<table>
<thead>
<tr>
<th>Table 2. Normal Ranges for BMP Values</th>
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<td>Sodium</td>
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<tr>
<td>135-145 mmol/L</td>
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<tr>
<td>Potassium</td>
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<tr>
<td>3.5-5 mEq/L</td>
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<tr>
<td>Bicarbonate</td>
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<tr>
<td>23-29 mEq/L</td>
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<tr>
<td>Creatinine</td>
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<tr>
<td>Men: 0.7-1.3 mg/dL</td>
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<tr>
<td>Women: 0.6-1.1 mg/dL</td>
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<tr>
<td>BUN</td>
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<td>7-20 mg/dL</td>
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<tr>
<td>Glucose</td>
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<tr>
<td>Pre-Meal: 70-130 mg/dL</td>
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<tr>
<td>Post-Meal (1-2 hours): &lt;180 mg/dL</td>
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into the bloodstream, kidney failure, deficiency of the hormones that regulate potassium excretion or a side effect of various medications. Since potassium is mostly eliminated from the body by the kidneys, people with chronic kidney disease who ingest foods with massive quantities of potassium may present with significant elevations of potassium in the serum. A mild degree of potassium elevation may be asymptomatic, but a severe elevation may be associated with weakness and cardiac arrhythmias. Severe potassium elevation in the blood is a medical emergency and needs to be managed rapidly.

Bicarbonate is a measurement of the acid/base status of blood. The normal range of bicarbonate in the blood varies between 23 and 29 milliequivalents per liter. The bicarbonate level provides insight into the acidity of the blood without having to perform more invasive tests such as the arterial blood gas. A higher bicarbonate level can suggest that the blood is too basic, which can be associated with medication side effects, loss of fluids in the gastrointestinal tract, aldosterone excess (one of the adrenal hormones) or severely low potassium levels. However, an elevated bicarbonate level can also represent an excessive retention of carbon dioxide in the lungs.

Conditions like chronic obstructive pulmonary disease and other conditions that lead to decreased ventilation of the lungs will lead to a buildup of carbon dioxide with a subsequent rise in bicarbonate level in the blood as a way of compensation. A lower than normal bicarbonate level suggests that the blood is too acidic, which could be caused by a multitude of metabolic disorders, kidney disease, ingestion of various chemicals/medications, starvation or inadequate tissue oxygenation. However, a low bicarbonate level may also represent systemic compensation for hyperventilation resulting in a decreased amount of carbon dioxide present in the lungs. Therefore, the bicarbonate level can provide essential clues to kidney and lung function, as well as many other metabolic processes, and it may serve as the impetus for physicians to order additional specific testing.

Creatinine and blood urea nitrogen (BUN) are two measurements in the BMP that look directly at kidney function. Creatinine generally runs between 0.7 mg/dL and 1.3 mg/dL for men and 0.6 mg/dL and 1.1 mg/dL for women. This discrepancy is due to the fact that creatinine is derived from muscle, and men on average have more muscle mass than women. The normal range of BUN is from 7 to 20 mg/dL. Lower creatinine or BUN levels are generally not a significant issue. Higher creatinine or BUN levels can indicate kidney disease, liver disease or heart failure. In addition, certain medications can lead to a rise of creatinine, so it is always important to report all medications that are being taken to a physician.

Lastly, the glucose level in the blood is helpful for diagnosing and/or monitoring diabetes. However, the glucose level can fluctuate depending on food ingestion. The normal pre-meal blood glucose range is between 70 and 130 mg/dL, and the normal one- to two-hour post-meal level should be less than 180 mg/dL. For non-diabetics, an elevated level may provide clues to physicians to run additional testing to assess the potential of diabetes. For diabetics, an elevated level would provide insight that the diabetes is not well-controlled and a more optimal diet/medical regimen should be implemented. For those on medications for the treatment of diabetes, a fasting blood glucose less than 70 mg/dL is indicative of hypoglycemia likely from insufficient nutrient intake or excessive anti-diabetic medication use. For non-diabetics, glucose of less than 70 mg/dL can be caused by increased insulin production or decreased glucose production in the body due to various disorders. Hypoglycemia is a potentially dangerous condition and often very symptomatic (weakness, anxiety, changes in mental status, sweatiness), and it needs to be addressed immediately.

**The BMP is an overview of the concentration of key chemicals in the blood that help the body function.**

**What the Basics Mean**

Overall, these basic laboratory assessments are very helpful tools that allow physicians to gain a clearer insight into the status of patients’ health. While they do not provide a specific diagnosis, they can often direct physicians toward a more targeted path of investigation to make the proper diagnosis and perform the appropriate management of a condition. In the era of modern medicine, patients need to play an active role in their health management, and with a better understanding of the fundamentals of routine laboratory tests, they can become a more informed and astute member of their healthcare team.

**BOB GENG**, MD, MA, studied medicine at Washington University School of Medicine in St. Louis, where he also completed his residency training in internal medicine. He is currently an assistant professor in allergy and immunology at the University of California, San Diego. Dr. Geng received his bachelor and master of arts degrees in Georgetown University’s School of Foreign Service.
**PROFILE:**

Jennifer Pate, MD

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**AS A TEENAGER,** Jennifer Pate had ambitions of making the professional tennis circuit, when a series of recurrent infections relegated her to the sidelines. Her eventual diagnosis of common variable immunodeficiency (CVID) changed the course of her life and her career plans. Today, Dr. Pate is a recognized psychiatrist who specializes in helping the chronically ill cope with their diagnosis.

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**Trudie:** How were you diagnosed with CVID?

**Dr. Pate:** I struggled with recurrent sinus and ear infections and episodes of pneumonia that would linger for weeks or more since I was 11 years old. When I was a senior in high school and preparing to launch a professional tennis career, I developed an unusual parasite infection. After my condition continued to worsen, I was admitted to Texas Children’s Hospital (TCH) and eventually diagnosed with CVID. I’ve been coming to TCH every three weeks for the past 30 years for life-saving intravenous immune globulin (IVIG) infusions. Without accurate diagnosis and treatment, I would not have survived.

**Trudie:** Why did you become a physician?

**Dr. Pate:** After seeing firsthand the importance of the doctor-patient relationship in helping patients manage chronic illness, I decided to go to medical school myself. I became a psychiatrist and am currently the chief of psychiatry at Baylor St. Luke’s Medical Center. I specialize in helping patients cope with serious chronic medical illnesses and have been named repeatedly in lists of America’s Top Psychiatrists — something I’m very proud of.

**Trudie:** Why psychiatry?

**Dr. Pate:** I care more about the people behind the illness than the actual symptoms or the medications involved, and I like to get to know people and help them with whatever experience they’re dealing with. So
psychiatry ended up being a great fit for me. It’s also less risky for someone like me with an immune deficiency, who really should avoid being around people who are sick.

Trudie: How has being a patient made you a better physician?

Dr. Pate: I clearly understand the anxiety, sadness, frustration, vulnerability and loneliness of being a patient better than I would if I were not chronically ill. My patients often compliment me and are shocked that I “get it” or understand their experience so well. I also have a unique view of the doctor-patient relationship. I know how patients want their doctors to communicate with them, and I also know what works in terms of how physicians interact with their patients.

Trudie: As a psychiatrist, what are the common issues you see facing patients with chronic illness?

Dr. Pate: Many of my patients are struggling with depression, anxiety, insomnia, chronic pain, substance abuse, delirium/hepatic encephalopathy, end-of-life issues and noncompliance. The theme of conflicts in the doctor-patient relationship is also very common.

Trudie: You had a serious health setback not too long ago. Tell us about that.

Dr. Pate: Three years ago while swimming laps in a neighborhood pool, I developed a life-threatening ear infection that has caused me to become deaf in one ear and required multiple operations, ongoing surgical care and long-term intravenous antibiotics. Despite these challenges, I continue to push forward and fulfill my passion for helping others even in the midst of this serious illness.

Trudie: What are your biggest challenges, and how do you overcome them?

Dr. Pate: Fatigue and hearing loss. With regard to the fatigue, I go to bed very early and plan my days around my energy level. For example, my best times are very early in the morning. I am much less likely to be productive after a long workday and rarely plan social activities during the work week. With regard to the hearing loss, I work with an outstanding ear, nose and throat doctor and audiologist, and I have a special type of hearing aid to compensate for single-sided deafness.

Trudie: Tell us about the fund you established at TCH and the motivation behind it.

Dr. Pate: On Feb. 17, my mother and I hosted a breakfast at TCH to honor my medical team for 30 years of outstanding care since my diagnosis of CVID. This was one of the happiest days of my life. We established a fund to support nursing education and also to help patients with exceptional medical expenses not covered by their insurance (hearing aids, noncovered medications, etc.). As a result of this fund, nurses have opportunities to attend conferences they would not have otherwise had access to.

Trudie: What is the best advice you’ve received as a patient and/or physician?

Dr. Pate: Dr. Tim Connolly, a critical care physician and dear friend of mine, has repeatedly used the metaphor “stay off the roller coaster.” I think this is excellent advice. Chronic illness brings with it multiple frequent stressors. Managing the illness is a load unto itself, and getting on the emotional roller coaster will only increase the weight of the burden.

Trudie: How do you stay positive?

Dr. Pate: I have wonderful family, friends and my dog. Knowing I make a difference in the lives of my patients is the reward that keeps me positive.

Trudie: What are your goals for the future?

Dr. Pate: I would eventually like to write a book to help patients and physicians understand the experience of chronic illness. As a young patient, I was certainly someone who saw my physicians as perfect and thought that they couldn’t have anything wrong with them. I think my story sends an important message to patients that it’s possible to overcome a lot of things and accomplish a lot, even with chronic illness.

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.
Beating the Bumps in the Road

By Ever Fecske Mazza

THE VAST MAJORITY of immune globulin (IG) patients are treated with much more than just IG. Most of us have a daunting list of other illnesses with medications that go along with them. I feel lucky that my weekly IG treatments are usually uneventful. But, it’s not always smooth sailing. I hit bumps in the road daily with my overall health. And it’s a challenge to cope with those bumps, especially the side effects from medications.

I’ve been doing subcutaneous IG treatments for the last four years; I was treated with intravenous IG for six years prior to that. Every Thursday evening, I infuse two 60mL syringes. I no longer have to be pre-medicated, and it takes me about 30 minutes to set everything up and about three-and-a-half hours to finish. I have infused in the car, on a camping trip and while nursing my son. I make it work so I don’t miss a party or a get-together with friends and family. I just strap my infusion pump around my waist and pretend it’s not there. And, I don’t have many side effects, just an occasional headache and some swelling and tenderness at the infusion sites. All in all, everything runs pretty smoothly.

Recently, my doctor prescribed four rounds of Rituxan to experimentally treat my granulomatous-lymphocytic interstitial lung disease. My doctors, family and I were all hoping it would work, and most of all, we were all hoping for an easy infusion experience. Over the years, if there is anything I have learned, it’s that sometimes the side effects from a medication are worse than the illness it’s treating.

I have a good friend, Nancy, who has been through a course of Rituxan, so it was comforting to be able to talk about my fear of the unknown. While she made me feel a lot better, I appreciated her honesty in telling me that the first infusion wasn’t easy for her. She became very short of breath and was coughing uncontrollably, almost like her throat was closing. She told me this is a normal reaction because the medication is so powerful that it starts killing cells from the neck down. When you get the feeling like your chest is tightening, she said, it’s just the medication doing its job.

The morning of my first infusion, I was nervous, but I felt I knew what to expect. I made sure I packed a lot of snacks, a book and a cozy blanket, as well as an abundance of cough drops just in case I had the same reaction as Nancy. I received my 50mg Benadryl and 120mg Solu-Medrol, and I passed out. All of a sudden, I felt a little tickle in my throat. I cleared it and tried to go back to sleep, but it wouldn’t go away. The tickle started getting worse, and I felt like I couldn’t get enough air. Sure enough, the coughing attack began. I tossed a cough drop in my mouth thinking it would help me go unnoticed, but I could already see the nurses staring at me with frowns on their faces. As the coughing continued, one nurse came over to ask if I was OK. But I could only get one word out between coughs, so she turned off the IV drip and called my doctor. Of course, he wasn’t in the office. So they spoke with a doctor on call who had no clue who I was and had never seen my chart. I was getting frustrated; I knew what was happening was normal, yet they were all panicking more than I was.

When the unknown doctor came to talk to me, she said she was considering stopping the treatment altogether. I then explained that there was no way I would be willing to postpone. I needed this treatment; it was my only hope for feeling better, and I would muscle through it. I asked her to just have the nurses slow down the infusion rate and to give me some more of the pre-medication. I know she didn’t like me telling her how to do her job, but in that moment, I was determined to advocate for myself the best I knew how. Feeling defeated and a little frightened because I knew we didn’t have a plan B, my infusion took a total of nine hours, but I finished! There were some adjustments that needed to be made to the orders, but I was able to receive the last three infusions without any trouble.

I just finished four rounds of Rituxan, and I am happy to report that my lungs are responding well to the treatment. My CT scan and pulmonary function tests have improved. I got over the bumps, and for the time being, I get to enjoy a deep breath whenever I want!

EVER FECSKE MAZZA was diagnosed with CVID and interstitial lung disease in 2004. She is a new 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!
Organizing Your Infusion Supplies

By Ilana Jacqueline

**IF YOU’RE LIKE** me, you’re always looking for someplace to store your infusion supplies, but those closets are so illogically packed, so unrealistically overburdened, that they’re about to burst open with old photo albums, Jenga and every birthday, graduation and engagement gift I ever received. Even if I wanted to store another pair of rollerblades or winter coats inside of them, I just couldn’t.

So, it’s no wonder I get a mild panic attack every time my infusion company drops off a massive box of supplies! Between the tubing and equipment, gauze, packaging and all of those teeny, tiny accessories, how am I supposed to keep this stuff organized?

I tried the “keep everything in a box” method, but all that did was slow down the entire process — digging around for the right tools, pulling out items I had already set up and constantly looking for that tiny plastic piece buried underneath. Plus, where exactly was I supposed to keep the giant box? Not in my closets; that much was obvious. So, I kept it in a hallway. And every time I walked down that hallway, it bothered me.

So like any modern 20-something I turned to Pinterest: the great mecca of organizing ideas. And I found a possible solution almost immediately.

Someone had recommended going to the Dollar Store and buying a plastic hanging shoe rack. You know, the kind with a fabric backing on a hanger and open slots of plastic to place each shoe in? Even though I didn’t have much room in those closets, I could actually hang this rack over all the junk that was already in there. I labeled each individual pocket with the name of the supplies (needles, tubing, alcohol pads, etc.), and it made finding what I needed so much quicker and easier! You can also hang the rack on the back of a bathroom door if you’re out of closet-hanging space. You can find these plastic organizers at Bed Bath & Beyond and Target, as well as the Dollar Store!

If you’re receiving infusions other than intravenous immune globulin, a shoe rack might not do it, though. I also get saline each day through an IV and found that Target had a great rolling, six-drawer plastic storage cart that fit all of my supplies really well. It reminds me a bit of the storage carts I’ve seen in ERs. It’s a quick and easy way to find exactly what you need, when you need it. I also keep a sharps container on top of it so I can easily throw out my needles without having to get up.

To take it one step further, I set up the cart, took each of the plastic bags the products had come packaged in and used them to create ready-made kits. I put all the materials for one infusion in a bag and left it in one of the drawers so that the next time I sat down to do an IV, I was ready to go. This will also be great for a trip I’m planning to take next month. I can easily grab my “to-go” packs and pop them in my suitcase without having to worry about whether I’ll have the right supplies.

The goal and philosophy for me always has been and always will be: This is an inconvenient medical issue; what can I do to make this as easy and as effective as possible so I can go about the rest of my life? So, take an hour or two to shop and organize your stash, and save yourself the drudgery of making your infusion a long and drawn-out affair. After all, you’re going to need that time to clean out your closets at some point.

**ILANA JACQUELINE** is a 24-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](http://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.
“Quaaaaack quack qu qu QUAAACK!” the momma duck cried, and I translate: “I know it’s really early in the morning, but I am trying to show you my freshly hatched ducklings. You know, the ones from the nest right next to your hot tub? Well, I’m the momma who’s been sitting on those eggs for what seems like forever. Anyway, we had just navigated our way across the street and were heading to your lush and oh-so-soft grass, when I heard ‘plop, plink, plink, plop, splash!’ That storm drain in the gutter in front of your lawn just gobbled up six of my precious ducklings! I completely forgot that the bars that cover the mouth of the drain are just the right size for baby ducklings and leaves to fall through. PLEASE GO GET MY BABIES!” This, of course, was a very loose translation; I’m not fluent in mallard.

“How many are in there?” I asked my eldest son, Calvin. “If we put some cardboard over the top would that help?” It was 6:45 in the morning and usually not the better-thinking part of my day.

“Mom, I’m too late for both school and duckies! They already fell into the drain, and I gotta go!” Calvin said, interrupting my foggy, early-morning thought pattern.

I waved goodbye to my boy as he sped off in my car, careful not to make our current situation worse by running over the frantic momma duck and her four landlubber ducklings.

My attention turned to Momma Duck calling out as if she had just dialed 911: “SQUAK, QUAAAAAAAK qu qu qu QUACK QUACK QUACK!” she cried until my husband, Mark, came out to get his car warmed up for his commute to work. Mark gave me a hug and said, “Well, gotta go!” He kissed me on the cheek and quickly made his way to his get-away truck. Momma Duck looked my way and restarted her bellyaching, since Mark was selectively listening.

“Stop right there!” I loud-whispered. “What am I supposed to do? Caleb and Molly have their infusions today. I’ve gotta get stuff ready for Nurse Nancy!”

“Call the fire department,” Mark said with a certain smile on his face that I’ve experienced before. “Love ya! I believe in you! Have a great day!” Mark proclaimed, waving goodbye like a princess.

I thought to myself: I’ve got 45 minutes before I have to get Molly and Caleb ready for their infusions. Do I even have time for calling the fire department? What in the heck is the fire department going to say when I ask them to come fish misguided ducklings out of a storm drain? Like they have time for that!

“Sure! We’ll see you in about 20 minutes or so,” Fire Chief Sam told me. And here I thought I’d be the laughingstock of the fire department. “We do this kinda stuff quite a bit this time of year. Just give us a few minutes, and we’ll be right over.”

We live in the country but very close to our local fire department. We pride ourselves on treating wild animals as food and multigenerational neighbors. Our family feels close to them, since our backyard is not only their nesting ground but also their “hook-up” spot. In late winter and early spring, we have to be mindful of backyard behavior among the mallards; dinner time is their perfect opportunity to “secure” the next generation’s existence on terra firma. Nonetheless, we do love our ducks in these parts, which is why I wasn’t completely taken aback when Fire Chief Sam agreed to be over as soon as they were done with their morning meeting.

What did cause me shock is when they rolled up in Engine #3.
“That’s some fancy wheels for a few lost duck-souls,” I said while shaking Fire Chief Sam’s hand.

“Nothing but the best for our community members,” Chief Sam replied, tipping his helmet toward our now extremely vocal momma duck. She began telling Chief Sam and the four other firemen who came to her rescue all about how three-fifths of her brood ended up on an unexpected field trip, when our primary immune deficiency disease kids, Caleb and Molly, came out of the house to see what was going on.

“You invited the fire department to our infusion, Mom?” Caleb asked. “Omigosh, I almost forgot! Nurse Nancy is on her way, isn’t she?”

“No, she’s running a bit behind. Something about a traffic jam of some sort she’ll tell us all about when she does manage to get here,” Molly said, bent at the waist and looking into the storm drain.

“How many fell in?” Caleb asked, joining his sister.

“Not sure. Maybe seven or eight?” Molly guessed.

“Well, we’d better get these little guys and gals outta the drain before their mother ‘quacks up.’ Get it? Quacks up?” Chief Sam joked, badly.

“We’d better get going with this rescue!” one of the firemen announced while wrapping a large hoe with duct tape. “So, who’s up for the task?”

“I’ll scoop ‘em up, but where to?” asked another one of the firemen. “The momma has unfortunately flown the coop!”

“You trying to out-bad-joke me?” Chief Sam asked.

“No, just being obvious. Where did she go?” the fireman asked.

Sure enough, our momma duck had disappeared. Between the stress of losing her babies and the very large fire truck that drove uber close to the drain where her babies fell, it must have been too much for her.

“We can still get them out, but I don’t want to just put them anywhere. They’re going to need to stay warm until they find Momma again,” Chief Sam concurred. “How about putting them in something like a towel-lined box until Momma finds them?”

As they debated how to safely reunite the duck family, Caleb and Molly figured it all out. The kids’ specialty pharmacy had upgraded their delivery boxes with an insulated liner.

“We’ve got it! Let’s put the babies in this insulated box! It’ll keep ‘em warm and safe until Momma comes and gets them!” Molly said.

As the firemen unhooked the grate, the ducklings really made a fuss. Either they were “peep-”ing for joy that someone was coming to rescue them or they were trying to sound fierce to scare away predators. In any case, all six ducklings were successfully rescued by the city’s finest — and quickest, since they had to chase down some of the more rebellious escapees through our neighbor’s rose bushes.

Caleb found a perfect spot to safely leave the box by the creek that runs through our backyard. And not more than 15 minutes later, the now-relieved momma duck heard her brood peeping away and managed to reunite them with their four nest mates. It was quite a (sniff) touching moment.

“So, what’s all the fuss about? I just said goodbye to the firemen in front of the house!” Nurse Nancy asked as she came to see what we were emotionally observing.

We shared our morning’s activities while getting ready for the kids’ infusions, when I finally got around to asking Nurse Nancy about the traffic jam she had in the country.

“You wouldn’t believe this, but there must have been 25 cars and trucks in front of and behind me on both sides of the highway waiting for a family of ducks to cross the road!”
Helping Your Child Balance Academics and Chronic Illness

By Jessica Leigh Johnson

IT CAN BE hard for parents of a child who suffers from chronic illness to think beyond the current infection or the next treatment. It’s only natural to focus most of our parental efforts and energy on keeping our child healthy. Unfortunately, this means that, sometimes, other aspects of “normal” life tend to take a backseat to the all-encompassing illness. While maintaining good health is important, our child’s education should also be a top priority.

According to Ron T. Brown, PhD, a leading pediatric psychologist specializing in children and adolescents with chronic illnesses, 27 percent of American children have a chronic illness.1 And, because of advancements in modern medicine and treatment options, these children can lead long, productive lives, but that doesn’t mean they won’t face occasional challenges, especially when it comes to their academic performance.

Chronically ill children, especially those in middle school and high school, can fall behind academically from too many doctor appointments and sick days. Parents, struggling to help their student keep up with his or her peers, may feel overwhelmed and pressured at times. Yet, while it’s true that parents are their child’s best advocate, they don’t need to go it alone when it comes to balancing chronic illness and education. There are plenty of people available to help both parents and their child achieve the best possible academic outcome — even while battling chronic illness.

Talk to the child’s doctor. It’s best to discuss your child’s health condition with your physician at the start of each school year. Prescription medications and treatments can be added and dropped from a child’s regimen frequently, with little to no thought as to how it could impact him or her academically. When starting a new treatment or medication, be sure to ask the doctor whether there are any side effects that might interfere with concentration, cognitive ability and meeting deadlines.2 Knowing this ahead of time will help parents and teachers understand why a normally attentive student suddenly seems to have trouble paying attention or staying on task.

Plan ahead. People are often advised to prepare for the worst and hope for the best. This is especially true when dealing with a chronically ill child. While parents hope that their child will maintain perfect health throughout the entire school year, it is unlikely that will be the case. It’s always best to be prepared for the unexpected by having an educational plan in place in the event of a health setback.

Parents should contact their local school district to see if their child qualifies for a 504 plan. Section 504 of the Rehabilitation Act and the Individuals with Disabilities Education Act (IDEA) specifies that “no child with chronic or life-threatening illness and/or disability can be excluded from participating in federally-funded programs or activities, including elementary, secondary or post-secondary schooling,” and all are entitled to educational support. A 504 plan will specify physical accommodations necessary to give a disabled or chronically ill student an opportunity to perform at the same level as his or her peers. Some
accommodations relating to chronic illness might include blood sugar monitoring, a peanut-free lunch environment or the availability of home instruction.3

Many children who miss school frequently due to illness or lengthy hospital stays also have individual education plans (IEPs). These are customized goals and learning strategies created by the student’s teachers, school psychologists, specialists (like speech therapists) and counselors that take your child’s individual needs into account to help him or her reach educational milestones.2 A child’s IEP will state his or her present level of academic performance, and list educational goals for that school year. Any special education support and services that the school will provide to help your child reach those goals will be spelled out in the IEP, along with special modifications and accommodations that will help your child make progress.4 Because some rare chronic health conditions are not well understood by the school personnel, parents should feel free to educate those involved in creating the IEP about their child’s condition, and suggest unique options and accommodations that might not otherwise have been considered.

Be flexible. Parents and students should feel free to talk to teachers and school staff regarding any issues that may arise during the school year. If a particular illness causes the child to miss a lot of school, it may be necessary to reduce the course load or extend due dates for projects, papers and tests.2 Give teachers as much notice as possible if any adjustments need to be made. This will allow them to find a more flexible solution that works for everyone.

It doesn’t hurt to plan your child’s academic schedule around his or her medical condition when possible, especially if there are certain times of the year when he or she is more frequently ill. For example, if the child suffers from severe allergies in the spring, or if he or she tends to get sick frequently during the cold and flu season in the winter months, parents can encourage their child not to take certain classes where class attendance is a necessity, such as an art class, shop class or speech and debate. Plan for your child to take these classes when he or she is more likely to be present in the classroom. For other classes like social studies, math or English, much of the work can be done at home and submitted to the teacher online.

It’s always best to be prepared for the unexpected by having an educational plan in place in the event of a health setback.

Keep a balanced schedule. Simply avoiding illness is the best way for your child to stay in the classroom and out of the sickbed, thereby leading to a better academic outcome. There are several things parents can do to help their child stay healthy, even with the challenge of today’s busy schedules. Promoting good hygiene and a well-balanced diet are two of the easiest ways to stay healthy. Another is stress management. When your child is not at school, allow him or her to take it easy. Between finishing schoolwork and meeting the demands of your child’s condition, there may be little time left to relax, but even so, parents should encourage downtime. Hanging out with friends, going to the gym or just sitting in a quiet place and reading for enjoyment are all ways to combat the stresses of academics and lead to a state of better health overall.5

Encourage your child to get plenty of rest and to pace himself or herself as lengthy or difficult homework assignments are tackled. Not only does staying up all night cramming for a test or finishing a project produce less-than-stellar grades, the loss of sleep can wear down the body and lead to illness. Parents are advised to be aware of their child’s upcoming assignments and tests, and encourage him or her to tackle the work a little bit at a time rather than all at once. Good study habits are something everyone should learn, not just the chronically ill.

Keeping up with the ever-increasing demands of school can be overwhelming for many kids, and living with a chronic disease only compounds the matter. Parents should remind their child to take it easy, and not be afraid or embarrassed if he or she falls behind. Help isn’t far away. Teachers, school counselors, doctors and friends are there to assist both parents and students in any way they can — all you need to do is ask.

Jessica 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.

References
REGULAR EXERCISE CAN improve mood, help to manage weight and cholesterol, boost energy and concentration, decrease stress, and improve strength and endurance. For patients with a primary immunodeficiency disease (PI), knowing the benefits of exercise, or recalling the enjoyment of athletic pursuits prior to diagnosis but feeling too physically limited to stay active, can be frustrating and even discouraging. Finding an acceptable exercise regimen while battling the fatigue and physical limitations that accompany chronic illness may be challenging, but it is not impossible, if you follow suggested guidelines.

Safety First

Before embarking on any new exercise program, always consult with your doctor. Depending on your physical condition, your doctor might recommend specific exercises designed to reduce pain or build strength. Other considerations include how long your exercise sessions can be and what level of intensity is safe. You may also want to consult with a physical or occupational therapist who can provide specific guidelines to help you avoid injury.

Exercise for Peace of Mind

The benefits of exercise are universal, but a recent study found that regular exercise relieves anxiety in chronically ill patients and may help improve quality of life. In the study, researchers reviewed 40 previous studies published from 1995 to 2007 on the effects of exercise in nearly 3,000 people diagnosed with a variety of chronic illnesses. They found that in 90 percent of them, those who exercised regularly had fewer symptoms of anxiety such as feelings of worry, apprehension and nervousness than people who did not exercise.

Making It Fun

Many people avoid exercise because they perceive it as boring or tedious. To boost motivation, begin by making a list of activities you enjoy such as nature walks, dancing or even gardening. Be willing to think outside the box, too; for those who are less mobile, there are exercises and strength-training activities that can be performed while sitting, watching television or even lying down. If you’ve been sedentary for an extended period of time, simply walking the dog is a good way to get moving again. Other helpful tips include:

- **Choose low-impact exercises.** Low-impact activities are easier on your joints, back and knees. Consider exercises like walking on the treadmill, yoga, Pilates, weight training, low-impact circuit training and swimming.
- **Keep an exercise journal.** Log the activities you perform and how you feel before, during and after. If you find yourself overly exerted or particularly sore, take note and adjust your routine accordingly.
- **Conserve your “spoons.”** If you live with a PI, you have only so much energy to spend in one day. Don’t overextend yourself or plan too many activities on the days you plan to exercise. Remember to stay hydrated by drinking plenty of water, and take extra time to rest and recover.
- **Eat to succeed.** A diet full of processed foods can cause excess inflammation in the body, leading to muscle and joint pain, as well as fatigue. Consult with a nutritionist to see if there are dietary changes you can make to help you succeed with your fitness goals.

Patients with PI experience many fluctuations in their health, stamina and energy levels from day to day. While establishing a regular fitness routine is beneficial, always listen to your body and avoid overexertion if your symptoms flare. Some fitness experts suggest breaking your fitness regimen into short intervals repeated several times a day; consider three 10-minute activities spaced several hours apart, rather than attempting a full 30-minute workout that leaves you wiped out the rest of the day. Whether you are able to walk around the block or merely walk around the living room, moving a little each day will help you build stamina and endurance. Be proud of your accomplishments!

TRUDIE MITSCANG is a contributing writer for IG Living magazine.

Reference

Thera-Band Resistance Bands

Thera-Bands are the only resistive exercise bands endorsed by the American Physical Therapy Association. They offer progressive resistance to build upper- and lower-body strength and mobility for rehabilitation or fitness. The use of elastic resistance rather than weight-bearing exercises minimizes pressure on the joints and decreases the risk of injury. They can also be used while traveling, sitting at home or even in the office. $20, theraband.com

Freedom2Move Home Exercise Program Exercise DVD

The Freedom2Move home exercise program and video series was designed by a doctor of physical therapy to allow for everyone’s participation and physical betterment. It can be performed by serious athletes, individuals who live with a chronic health condition or those who are unable to move at all without assistance. Viewers get a customized workout and also learn about the targeted muscles, and how strengthening and conditioning them can lead to improved health and function. $19.99, freedom2move.org

Swiss Ball

Swiss exercise balls increase core balance and abdominal fitness. The TheraGear Swiss Exercise Pro Ball features extra thick walls for durability during a workout and maximum firmness and support. If the ball is punctured, it will deflate safely and slowly. It is burst-proof up to 500 pounds and has a 2,200-pound static weight limit. $48.95, swissball.com

SuuRuuS Shoulder Strengthening Resistance Rope and Pulley Set

The SuuRuuS shoulder rope pulley set is designed to help people recovering from injury or to increase range of motion. Recommended by doctors, physical therapists, occupational therapists and personal trainers, the set is easy to use by attaching to a doorway. Because of its compact size, it is ideally suited for travel, too. $10, Amazon.com

Fitbit One Wireless Activity Plus Sleep Tracker

The Fitbit One tracks steps, distance, calories burned and stairs climbed. At night, it measures an individual’s sleep cycle to help with better sleep. Stats upload wirelessly via computer or smartphone and allow individuals to set goals and track progress. Food, workouts and more can also be logged. $99.99, fitbit.com

exercise products to keep you moving!

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**BOOK CORNER**

**Life Disrupted: Getting Real About Chronic Illness in Your Twenties and Thirties**

Author: Laurie Edwards  
Publisher: Walker and Company

*Life Disrupted* is a personal guide to living well with a chronic illness. Sections include how patients can manage their own healthcare without letting it take over their life, dealing with difficult doctors and frequent hospitalizations, having a productive and satisfying career that accommodates health needs, and nurturing friendships and a loving, committed relationship regardless of recurring health problems. The author shares her own stories, the experiences of others with chronic illness and the advice from life coaches, employment specialists and health professionals.

**Beyond Casseroles: 505 Ways to Encourage a Chronically Ill Friend**

Author: Lisa J. Copen  
Publisher: Rest Ministries Publishers

Lisa Copen has written this book with a mix of the author's heartfelt wisdom, personal experience and humor to help people understand the challenges individuals with chronic illness face and how to minister to their needs. It is filled with a list of 505 ways to encourage a friend — from what to say, what not to say, things to write in cards or emails, gift ideas, things to bring when visiting in the hospital or someone at home, and the list goes on. The ideas are simple, practical and creative.

**The Healthcare Handbook: How to Avoid Medical Errors, Find the Best Doctors, Be Your Own Patient Advocate & Get the Most from Healthcare**

Author: Gwen van Servellen, MD  
Publisher: HealthcareBooks.net

This book is written by a UCLA professor emeritus with 35 years of experience evaluating patient care. In the book, Dr. Servellen discusses why medical errors happen and how to prevent them; the secret to finding the best doctors and when to choose a new one; how to communicate effectively with your doctor or healthcare facility; how to make sure your health records are kept accurately; and key strategies for managing your treatment process to get the best outcome.

**How to Start a Chronic Illness Small Group Ministry**

Author: Lisa J. Copen  
Publisher: Rest Ministries Publishers

Drawing from more than a decade’s worth of feedback from hundreds of Christian small groups for those with chronic illness, Lisa Copen guides readers through their concerns, worries and questions and helps them put their passion into action. This book discusses what a chronic illness is and whether it matters if it’s invisible; a brief history of illness ministry in the medical community; benefits of small group ministry for the individual and the church; how to lead when ill; steps to formulate the purpose of a small group (the logistics, guidelines and vision); preparing a presentation to church leadership; planning the first meeting; promotion and attendance tips; maintaining a positive group when things get difficult; how to answer tough questions about healing and suffering; and a special chapter on ways a church can make a significant difference in the lives of the chronically ill. Also included is a checklist to follow along while planning.
For a more comprehensive list of resources, visit the Resources page at IGLiving.com.

**Ataxia Telangiectasia (A-T)**
- [WEBSTES](#)
  - A-T Children’s Project: www.atcp.org

**Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)**
- [WEBSTES](#)
  - 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)**
- [WEBSTES](#)
  - GBS/CIDP Foundation International: www.gbs-cidp.org
  - The Neuropathy Association: www.neuropathy.org

**Idiopathic Thrombocytopenic Purpura (ITP)**
- [WEBSTES](#)
  - ITP Support Association – UK: www.itpsupport.org.uk
  - Platelet Disorder Support Association: www.pdsa.org

**Kawasaki Disease**
- [WEBSTES](#)
  - American Heart Association: www.heart.org/HEARTORG/Conditions/More/CardiovascularConditionsOfChildhood/Kawasaki-Disease_UCM_306777_Article.jsp#T1T2booFWE0
  - Kawasaki Disease Foundation: www.kdfoundation.org
  - KidsHealth: kidshealth.org/parent/medical/heart/kawasaki.html

**Mitochondrial Disease**
- [WEBSTES](#)
  - United Mitochondrial Disease Foundation: www.umdf.org
  - MitAAction: www.mitaction.org

**Multifocal Motor Neuropathy (MMN)**
- [WEBSTES](#)
  - The Neuropathy Association: www.neuropathy.org

**Multiple Sclerosis (MS)**
- [WEBSTES](#)
  - All About Multiple Sclerosis: www.multiple-sclerosis.org/index.html
  - Multiple Sclerosis Association of America: www.msaa.com
  - National Multiple Sclerosis Society: www.nationalmsociety.org

**Peripheral Neuropathy (PN)**
- [WEBSTES](#)
  - 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)**
- [WEBSTES](#)
  - Immune Deficiency Foundation: www.primaryimmune.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
  - 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

**Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)**
- [WEBSTES](#)
  - P.A.N.D.A.S. Network: pandasnetwork.org
  - Midwest PANS/PANDAS Support Group: www.giveforkids.com

**Pemphigus and Pemphigoid**
- [WEBSTES](#)
  - The International Pemphigus and Pemphigoid Foundation: www.pemphigus.org

**Scleroderma**
- [WEBSTES](#)
  - Scleroderma Foundation: www.scleroderma.org
  - Scleroderma Research Foundation: www.srfcure.org
  - Scleroderma Center: www.hopkinsmedicine.org/rheumatology/clinics/scleroderma_center.html

**Stiff Person Syndrome (SPS)**
- [WEBSTES](#)
  - American Autoimmune Related Diseases Association Inc.: www.aarda.org
  - Genetic Alliance: www.geneticaalliance.org
  - Living with Stiff Person Syndrome (personal account): www.livingwithspss.com
  - Stiff Person Syndrome: www.stiffpersontersyndrome.net
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Tony
Golf enthusiast
living with PI
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Patient Advocates

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