COVID-19 and Loneliness

Tips for Thriving During the Pandemic

The Comforting Benefits of Assistance Dogs

Staying Fit at Home by Practicing Balance

Choosing a Caregiver for Your Loved One

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Maintaining Your Health in Uncertain Times

WHILE THERE appears to be promise for the pandemic’s end, we are still grappling with the effects of social distancing and stay-at-home recommendations. Bearing this in mind, we continue to offer suggestions to help you manage the pandemic’s effects.

For starters, we know many of you are dealing with a deeper sense of loneliness. Not only must you continue to limit exposure to others due to your chronic illness, but many of you have been forced to quarantine away from family and friends. And, research shows such solitude can have dire consequences on individuals’ physical and mental health. Fortunately, there are measures you can take to maintain contact with others to decrease feelings of isolation. In our article “Fighting the Loneliness of Chronic Illness” (p.22), we provide some useful tips for combating loneliness: taking online courses to learn new skills, practicing cognitive behavioral therapy and positive thinking, taking advantage of online platforms and smartphones to connect with others and travel in the comfort of your home, and even adopting a pet. The opportunities are as boundless as the Internet.

Speaking of pets, dogs make wonderful companions, especially assistance (service) dogs, which can lower stress, assist with everyday tasks and even alert you to a potential medical emergency. As we discuss in our article “This Dog’s for You: The Benefits of Assistance Dogs” (p.26), it’s amazing how sensitive dogs’ olfactory senses are, making them extremely advantageous in medical emergencies. In addition, studies have shown those who partner with assistance dogs have better emotional and physical health, thanks to canines’ improving their partners’ independence, social relationships, self-esteem and life satisfaction. If you are considering partnering with an assistance dog, we provide some resources for your consideration. But, be cautioned that caring for and providing a safe environment for an assistance dog is just as important as the aid and companionship the dog will provide to you.

Finally, finding balance in your life during these trying times is incredibly important. This means keeping your whole body fit, physically and mentally. As physical therapist Matthew Hansen explains in his article “Staying Fit at Home” (p.30), fitness is much more than physical strength and endurance; it also involves eating nutritiously, getting the proper amount of sleep and taking care of your mental and spiritual health. Try some of his helpful recommendations to improve and maintain your overall health during these especially trying times.

As always, we hope you enjoy these articles, as well as the many more educational and insightful topics presented in this issue of IG Living.

Ronale Tucker Rhodes, MS
By Abbie Cornett

**Conventional Versus COVID-19 Vaccines**

A LITTLE more than a year ago, the novel coronavirus disease, commonly known as COVID-19, rapidly spread across the globe, and obscure terms such as “pandemic,” “herd immunity,” “superspreader” and “social distancing” became common. In response, the world’s medical community devoted its efforts to developing a vaccine in “warp speed,” which has led to misunderstandings about how the new vaccines differ from conventional vaccines.

Conventional vaccines contain an antigen (a toxin or other foreign substance) that is injected into the body to activate the immune system. These vaccines come in different forms:

- Live attenuated vaccines (containing a weakened bacteria or virus)
- Whole inactivated vaccines (containing a killed bacteria or virus)
- Subunit and conjugate vaccines (containing the purified antigen part of the bacteria or virus)
- Toxoid vaccines (derived from inactivated toxins from bacteria)

Most conventional vaccines are made from viruses grown in chicken eggs or mammalian cells, a process that is complex and can take months before they are ready for distribution. Further, the development of a vaccine for a brand-new virus such as SARS-CoV-2 (the virus that causes COVID-19) can take years, not including the time needed for testing.

Because the rapid spread of COVID-19 created an urgent need for the development of a new vaccine, scientists around the world turned to a technology that uses messenger RNA (mRNA) (a nucleic acid present in all living cells whose principal role is to act as a messenger carrying instructions from DNA (a long molecule that contains our unique genetic code for controlling the synthesis of proteins) to create a synthetic version of the RNA used to form proteins. There are significant advantages to a vaccine created from this method. First, mRNA vaccines don’t contain enough genetic information to produce viral proteins. Instead, they contain just enough to trick the immune system into thinking the virus is present, so it will make protective antibodies and stimulate T cells. Second, mRNA vaccines can be made quickly.

Unfortunately, the speed in developing COVID-19 vaccines using this technology has resulted in the spread of incorrect information such as:

**Myth:** The vaccine is unsafe due to its rapid development.

**Fact:** While the vaccines were developed rapidly, the mRNA technology has been around for more than 30 years, and it may be safer than traditional vaccines. Drew Weissman, MD, PhD, an immunologist at the University of Pennsylvania whose laboratory focuses on the study of RNA and innate immune system biology, says in some very rare cases, the virus in traditional vaccines may not be dead despite best efforts to kill it, or the attenuated dose can be so strong it makes some people sick. mRNA vaccines eliminate those concerns because they do not contain any live virus.

**Myth:** People who have already had COVID-19 don’t need to get the vaccine.

**Fact:** Even those who have already had COVID-19 may still benefit from getting vaccinated. Due to the severe health risks associated with COVID-19 and the fact that re-infection with COVID-19 is possible, it is still recommended people who have previously had the illness and recovered get the vaccine.

**Myth:** mRNA vaccines change people’s DNA.

**Fact:** mRNA does enter cells, but not the nucleus where DNA is located. Once in the cells, mRNA causes those cells to create proteins to activate the immune system. When this is done, mRNA breaks down quickly, all without affecting DNA.

**Myth:** People who get the vaccine will not need to wear a face mask.

**Fact:** Those who are vaccinated still need to wear a mask! While the Pfizer and Moderna vaccines are 95 percent effective at preventing the virus two weeks after the second shot, and studies show cases are milder in those 5 percent who may get infected, there is still a 5 percent chance of getting infected and passing along the virus to others.

**Myth:** The vaccines are more dangerous than COVID-19.

**Fact:** The vaccines are not more dangerous than COVID-19. The vaccines can cause mild or moderate short-term reactions in some people that resolve without complication. But, these reactions are not more dangerous than the virus.

**References**


Abbie’s Corner

ABBIE CORNETT is the patient advocate for IG Living magazine. She can be reached at patientadvocate@igliving.com or (800) 843-7477 x1366.
How Have You Dealt with the Emotional Toll of 2020?

2020 was a piece of cake. [For those of us] who have been battling an autoimmune disease for many years, it’s just another year. Mostly business as usual for me. The infusions don’t stop for a pandemic. As for the mask thing, heh, this time of year I enjoy the mask. It keeps my face warm, and also reduces my chance of catching a cold. So far this year, I haven’t caught the cold/flu. Normally, I’m very sick around now. So, I’d say it’s helped me be a cleaner me.  

— Peggy SG

Music and comedy. Emotionally being there for others has helped. My “normie” friends, many of whom don’t know about masks and crowds [and] some who live in states where there is no mask mandate, have worn them in spite of ridicule. I try to be there for others; that helps my zebra friends, my family and normies because these are unprecedented times. Being cavalier — this is not the time.  

— Linda JC

Is Fatigue the Worst Symptom of Your Chronic Illness?

For me, chronic pain is the absolute worst! Pain can change the way you see the world. Fatigue can really put you down too, though. I’ve had it creep up on me like a blanket, and you have no choice but to lie down. It’s comparable with the feeling of going under anesthetic. I think we all feel alienated by our bodies at times. Having a supportive group of people going through the same challenges helps tremendously with the alienation. Groups like this give us validation. Validation is great for the mind. Thank you for giving us this platform, IG Living, and your topics are always on point.  

— Patricia MP

It is one of the worst symptoms of my disease. Sometimes I can’t tell which one is worse when I am hit with more than one issue. I consider it a “good thing” when I am hit with only one of these possibilities!  

— Jenny G

I think the chronic pain and fatigue are both awful. Unfortunately, as we all know, there aren’t any really effective treatments for fatigue. In that way, yes, fatigue is the worst and most debilitating symptom of my illness.  

— Mary-Jane M

Has Having a Chronic Illness Disrupted Your Career?

Well, my career ended years before my diagnosis, so I can’t say that. I stopped working in 2007, filed for Social Security Disability and kept fighting for years until I finally received Social Security in 2013. I was diagnosed in 2014.  

— Rachel D

Chronic illness meant something else prior to COVID-19. When you add the two together, if you don’t get “fear,” you might get death. Don’t get me wrong. I know the exact same virus is different for everyone, but it doesn’t come with a safety label affirming that you or your entire family will survive. I’d prefer we all still be here when it’s over. Much love to my chronic illness and IG Living family.  

— Patricia MP

Join the conversation! Connect with other immune globulin patients through IG Living’s Facebook page at www.facebook.com/IGLivingMagazine. Each day, we post interesting articles and facts, as well as thought-provoking questions you can weigh in on. These are some snapshots of what’s being discussed.
**Ask the Experts**

**Can a patient remove untrue and negative comments made by a doctor from his or her medical record?**

I had a doctor who wrote some very unfair and negative comments in my medical record that, besides being untrue, are preventing me from getting the care I need. How can I review my medical records, and is it possible to have the untrue comments removed?

**Abbie:** The Health Insurance Portability and Accountability Act (HIPPA) Privacy Rule establishes minimum federal standards for protecting the privacy of individually identifiable health information. In addition, the rule gives individuals certain rights pertaining to their medical records, including rights to access and amend their health information and to obtain a record of when and why their personal health information has been shared with others for certain purposes. This means health insurers and providers who are covered entities must comply with your right to review your records. Further, you may request a copy of those records and ask to have corrections added to your health information. If the provider or plan does not agree to your request, you have the right to submit a statement of disagreement that the provider or plan must add to your record. HIPPA also allows you to file a complaint if you believe your rights are being denied. For information about your rights under HIPPA, go to www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html.

**Will IG Eventually Contain Antibodies to COVID-19?**

Will immune globulin (IG) eventually contain antibodies to the COVID-19 virus from donors who have recovered from it? If yes, will this also apply to IgA-depleted serum to treat those with antibodies to IgA even though the serum undergoes additional processing to achieve the depletion?

**Abbie:** I spoke with Leslie J. Vaughan, RPh, chief operations officer at Nufactor, a Specialty Infusion Company, and H. Kobayashi, MD, an allergist and immunologist in Omaha, Neb., regarding your question. They said that if enough people exposed to COVID-19 develop antibodies, it is reasonable to assume IG produced from that plasma may contain antibodies. But, unless the U.S. Food and Drug Administration requires manufacturers to test for COVID-19 antibodies, it may never be known whether they are present. Assuming mass exposure and antibody development in the next several months, IG would likely contain COVID-19 antibodies nine to 12 months post-peak exposure. Therefore, there likely won’t be any antibodies in IG products for a long time, minimally a year.

There has been very little IgA in IG products since the 1980s, and there is even less now. Further, the commercial products that eventually contain anti-COVID-19 antibodies will be prepared in the same way, so it will be safe. Many patients with common variable immune deficiency and particularly those with X-linked agammaglobulinemia have low or no IgA [secretory or otherwise] and yet have little or no infections after starting IG replacement therapy.
HAVE YOU ever been in a situation when something you had to do was so scary you were unable to do it? Or, have you ever been so overwhelmed by your feelings that they got in your way of accomplishing something you really wanted to do? For example, perhaps you had a lot of anxiety about going to the doctor, so you cancelled the appointment. Or, maybe you wanted to make plans with friends but worried you may have to cancel them if your physical symptoms worsened, so you simply avoided making plans.

What about the opposite situation? Have you ever been faced with a situation that caused you a lot of anxiety, but you did it anyway? For example, perhaps you were afraid to go to the dentist, but you went anyway because you value your health. Or, maybe you wanted to try something new even though you worried you might embarrass yourself or fail, but tried anyway.

Uncomfortable physical sensations, thoughts and feelings can prevent us from doing things we want if we let them. Alternatively, they can propel us to move toward our goals and values. However, the latter is challenging, and it takes a lot of practice. It requires us to choose to do things even though we will experience uncomfortable thoughts and feelings.

To move toward our goals and values, we can choose one of two paths: 1) spend our time and energy trying to distract ourselves from or control the uncomfortable bodily sensations, pain, thoughts or feelings, or 2) let them be there and live our lives.

One of the most difficult things about moving forward when we have intense physical sensations, feelings or thoughts is it can be hard to remember we have a choice. So, how can we help ourselves to choose to move forward?

1) One way is to ask yourself some questions. For example:
   - If that thought (or emotion, bodily state, memory) could give advice, would the advice point you forward in your life or keep you stuck?
   - What would you advise someone else to do?
   - What does your experience tell you about this solution? And what do you trust more: your mind/feelings/body or your experience?

   Asking these types of questions when faced with doubt is more helpful than listening to what our minds come up with or what our impulses and urges are telling us to do. The answers remind us past solutions have not worked, and we can choose to do something different.

2) Another way is to practice “STOPP”ing.
   - Stop: Just take a pause!
   - Take note: What feelings and thoughts are happening? What thoughts are going through your mind? Where is your focus of attention? What are you reacting to?
   - Open up: Are you willing to feel this feeling, or do you want to try to get rid of it?
   - Pursue your values: What do you value in this situation? What are some things you can do to move toward your values?
   - Practice what works: Consider different options and their pros and cons. What is the best thing to do for you? What is the best thing to do for those you care about?

   Every day, we can commit again to behave in ways that move us toward the things we care about. This is not about committing to a particular result such as being in a steady relationship by next year or feeling less angry. Results are beyond our control. We all fall short of our goals at times. When that happens, we have the choice to either give up or recommit to small actions that make our lives meaningful. As long as we keep recommitting, we are moving forward in life.

ERIKA LAWRENCE, PhD, is director of translational science at The Family Institute at Northwestern University, Evanston, Ill.
**Type II Hypersensitivity: Summary**

**By Terry O. Harville, MD, PhD**

**TYPE II** hypersensitivity was described as a histopathologic observation by Gell and Coombs in 1963. Later, it was demonstrated to be due to antibodies binding directly to cell surfaces or to proteins and tissues that surround and connect cells together. Typically, IgG (primarily subclasses 1, 2, and 3, but not 4) and IgM antibodies are involved, followed by activation of the complement system, which results in holes through cell membranes that can cause cell damage and death. Normally, this is one of the mechanisms of the immune system to protect against invading microorganisms.

Type I hypersensitivity, involving IgE and the activation of mast cells, contrasts with type II hypersensitivity. The former causes true allergic disease, whereas the latter causes cell and tissue injury commonly seen in autoimmune diseases. Thus, type II hypersensitivity is not a true allergy. Type II hypersensitivity is also known as direct-antibody cytotoxicity or cell cytolysis. The Table lists diseases for which type II hypersensitivity is thought to be involved, along with the target cells or tissues and clinical manifestations.

Under normal circumstances, an infusion of intravenous immune globulin (IVIG) can cause a slight decline in the recipient’s hematocrit (the ratio of the volume of red blood cells to the total volume of blood), with clinical indicators that some hemolysis has occurred. Likewise, the platelet count may fall slightly in some recipients of IVIG. Usually, these are mild reactions and not considered to be clinically relevant, and specific antibodies causing the issues cannot typically be found. Yet, if a person has somewhat compromised kidney function, and even if the adverse reaction is considered to be mild, hemoglobin from lysed red blood cells could actually result in acute renal failure. This reaction is very rare, but awareness of this complication is needed to minimize potential morbidity from otherwise normal infusions of IVIG.

Furthermore, there may be risks for type II hypersensitivity reactions from IVIG infusions since offending antibodies may be present from some plasma donors. Since autoimmune diseases with autoantibodies are actually quite common (thought to occur in 5 percent to 8 percent of people), autoantibodies may also be considered quite common in potential plasma donors. It is reassuring that the screening process for plasma donor selection not only helps prevent transmission of infectious diseases such as hepatitis C and HIV, but also helps prevent those with significant autoimmune disorders from donating. Even if a plasma donor has made specific autoimmune antibodies, but has not been excluded from donating, that plasma will be mixed with as many as 10,000 other units of plasma, greatly diluting most significant autoimmune antibodies. Therefore, even though it is theoretically possible infusion of autoimmune antibodies could result in a reaction in IVIG recipients, the safeguards in place make this unlikely to occur.

Nevertheless, IVIG infusions should not be cavalierly performed. Medications need to be available, along with personnel who can help, if a reaction occurs. Further, if a severe reaction occurs, the IG brand and lot number must be reported to the U.S. Food and Drug Administration so appropriate evaluations can be performed (for example, to determine if a significant autoimmune antibody is present in that specific lot). If that is the case, the lot could be removed from use to prevent others from having severe reactions or worse.

Next time, we will begin with a discussion of the type III hypersensitivity reaction.

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**Table. Clinical Manifestations of Some Examples of Type II Hypersensitivity Reactions**

<table>
<thead>
<tr>
<th>Disease</th>
<th>Target</th>
<th>Clinical Manifestation(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute rheumatic fever</td>
<td>Heart tissue</td>
<td>Myocarditis</td>
</tr>
<tr>
<td>Autoimmune hemolytic anemia</td>
<td>Red blood cells (RBC)</td>
<td>RBC hemolysis/anemia</td>
</tr>
<tr>
<td>Autoimmune thrombocytopenia</td>
<td>Platelets</td>
<td>Low platelet count/bleeding</td>
</tr>
<tr>
<td>Goodpasture syndrome</td>
<td>Lung and glomerular basement membranes</td>
<td>Hemoptysis (coughing up blood)/hematuria (blood in the urine due to kidney injury)</td>
</tr>
<tr>
<td>Graves’ disease</td>
<td>Thyroid stimulating hormone receptor</td>
<td>Hyperthyroidism</td>
</tr>
<tr>
<td>Hemolytic disease of the fetus and newborn</td>
<td>Rho or D antigen (Rh or Rhesus factor)</td>
<td>Severe anemia/cardiac problems/hydrops fetalis</td>
</tr>
<tr>
<td>Myasthenia gravis</td>
<td>Acetylcholine receptor</td>
<td>Muscle weakness or paralysis</td>
</tr>
<tr>
<td>Pemphigus vulgaris</td>
<td>Desmosomes (protein complex for attaching cells to each other)</td>
<td>Loss of cell contact resulting in tissue layer separation and large blister formation</td>
</tr>
<tr>
<td>Pernicious anemia</td>
<td>Intrinsic factor</td>
<td>Anemia due to the lack of absorption of vitamin B12</td>
</tr>
<tr>
<td>Transfusion reaction</td>
<td>ABO mismatch/other RBC antigens</td>
<td>Acute hemolytic anemia</td>
</tr>
<tr>
<td>Type 1 diabetes mellitus</td>
<td>Islet cells of the pancreas</td>
<td>Diabetes (high blood glucose levels)</td>
</tr>
<tr>
<td>Vasculitis due to ANCA</td>
<td>Cytoplasmic proteins in neutrophils</td>
<td>Vasculitis (inflammation of blood vessels)</td>
</tr>
</tbody>
</table>

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PREDNISONE IS a generic name for a potent anti-inflammatory medication, as well as an immunosuppressant agent, prescribed to treat numerous conditions and symptoms. And, while it’s highly effective, it can come with many side effects, especially when used in high doses and for a long period of time.

Conditions Prednisone Treats
Prednisone is a corticosteroid and, more specifically, a glucocorticoid, which is a hormone. The body naturally makes glucocorticoids that have various functions involving inflammation control, which is an immune response to injury or infection. Glucocorticoids are highly effective at curbing this immune response and reducing inflammation when it is too strong. That’s why prednisone is used to treat so many conditions. For instance, prednisone is prescribed as a first-line treatment, often in high doses, for autoimmune diseases in which the immune system malfunctions and attacks itself, causing injury and inflammation. Prednisone is also used to treat lung conditions such as asthma and chronic obstructive pulmonary disease to reduce inflammation in the lungs to allow easier breathing. And, it can be used to treat Crohn’s disease and other inflammatory bowel conditions, arthritis and allergies.

Treatment Goal
The goal of treating a disease with prednisone is to control symptoms caused by the inflammation and then discontinue its use. If prednisone is prescribed in a lower dose and for a very short period such as a week or two, it can be started and simply stopped. If it’s prescribed in a higher dose and for a longer period, discontinuation must be weaned, meaning the dosage has to be gradually reduced. Abruptly discontinuing prednisone could result in withdrawal and some unpleasant and even dangerous symptoms. This is because prednisone is similar to cortisol, a hormone produced by the adrenal glands, so those being treated with it produce less cortisol, meaning they need time for the body to resume normal function. Prednisone withdrawal symptoms include:

- Extreme fatigue and weakness
- Joint and muscle pain and/or tenderness
- Lightheadedness
- Difficulty breathing
- Loss of appetite and weight loss
- Headache
- Psychological reactions such as depression, anxiety and mood swings

Additionally, although rare, a possible fatal reaction called an adrenal crisis could occur if prednisone is stopped and cortisol levels are too low. Therefore, it’s vital for patients to follow the weaning protocol exactly as instructed and report any potential withdrawal symptoms immediately.

Side Effects of Long-Term Use
While taking prednisone, a host of side effects can occur. Additionally, complications can occur from long-term use. For instance, long-term use can impact normal adrenal gland function. Symptoms that may signify problems with the adrenal glands include blurry vision, dizziness, fainting, a fast and/or irregular heartbeat, changes in urination and extreme fatigue and weakness.

The ordering physician should be immediately notified if any side effects become concerning, severe and/or bothersome. This is especially true if side effects appear to be related to the adrenal glands. It’s also important the physician is aware of all other medications patients are taking, including over-the-counter medicines, as well as all past and present conditions. Some conditions may be contraindicated for prednisone use, especially high-dose and long-term use. For instance, prednisone can cause blood glucose elevation, so people with
diabetes who are taking prednisone need to carefully monitor blood sugar, comply with any diabetes medication and adhere to their diet and exercise regimens. Any changes in blood sugar or high blood glucose need to be reported immediately.

Risk of infection is another side effect of prednisone since it suppresses the immune response. Therefore, it’s important for patients to adhere to proper and frequent handwashing and to avoid sick people. If there are any signs and symptoms of infection, the ordering physician should be informed right away.

Prednisone can also affect appetite, weight and mood since it’s a hormone. In fact, increased appetite is quite common. Stomach irritation can also occur, so taking it with food or milk can help alleviate this. If the irritation becomes severe, gastric ulcers and even gastrointestinal bleeding could result. Too, mood changes should be monitored, and any longer-lasting depression and/or anxiety should be discussed with the ordering physician. Also, because prednisone can cause insomnia, it’s best for patients to take it in the morning.

Another downside of prednisone is its effect on bone density, which can lead to osteoporosis and even fractures. The body’s ability to produce strong, dense bones is a juggling act between natural processes that build up bone and those that break it down. Corticosteroids tend to both reduce the body’s ability to absorb calcium and increase how fast bone is broken down. The longer the therapy continues, the greater the potential for loss of bone density. The ordering physician can determine if there is a need to monitor bone density via scans and if supplements such as vitamin D and/or calcium are necessary. Exercise can also help bone growth and retention. Clearly, it’s wise for patients to be aware that prednisone can affect virtually every system in the body and sometimes result in a wide variety of unpleasant side effects (Table).

**Highly Effective but Caution Is Needed**

In summary, prednisone is highly effective in controlling inflammation in a variety of conditions. But it’s important to understand the side effects and complications that can occur while taking this medication to offset and minimize untoward effects.

**References**


**Table. Side Effects of Prednisone**

<table>
<thead>
<tr>
<th>More Common</th>
<th>Incidence Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Aggression</td>
<td>• Abdominal or stomach cramping or burning (severe)</td>
</tr>
<tr>
<td>• Agitation</td>
<td>• Abdominal or stomach pain</td>
</tr>
<tr>
<td>• Blurred vision</td>
<td>• Backache</td>
</tr>
<tr>
<td>• Decrease in the amount of urine</td>
<td>• Bloody, black or tarry stools</td>
</tr>
<tr>
<td>• Dizziness</td>
<td>• Cough or hoarseness</td>
</tr>
<tr>
<td>• Fast, slow, pounding or irregular heartbeat or pulse</td>
<td>• Darkening of the skin</td>
</tr>
<tr>
<td>• Headache</td>
<td>• Decrease in height</td>
</tr>
<tr>
<td>• Irritability</td>
<td>• Decreased vision</td>
</tr>
<tr>
<td>• Mood changes</td>
<td>• Diarrhea</td>
</tr>
<tr>
<td>• Noisy, rattling breathing</td>
<td>• Dry mouth</td>
</tr>
<tr>
<td>• Numbness or tingling in the arms or legs</td>
<td>• Eye pain</td>
</tr>
<tr>
<td>• Pounding in the ears</td>
<td>• Eye tearing</td>
</tr>
<tr>
<td>• Shortness of breath</td>
<td>• Facial hair growth in females</td>
</tr>
<tr>
<td>• Swelling of the fingers, hands, feet or lower legs</td>
<td>• Fainting</td>
</tr>
<tr>
<td>• Trouble thinking, speaking or walking</td>
<td>• Fever or chills</td>
</tr>
<tr>
<td>• Troubled breathing at rest</td>
<td>• Flushed, dry skin</td>
</tr>
<tr>
<td>• Weight gain</td>
<td>• Fruit-like breath odor</td>
</tr>
<tr>
<td>• Abdominal or stomach cramping or burning (severe)</td>
<td>• Full or round face, neck or trunk</td>
</tr>
<tr>
<td>• Abdominal or stomach pain</td>
<td>• Heartburn or indigestion (severe and continuous)</td>
</tr>
<tr>
<td>• Backache</td>
<td>• Increased hunger</td>
</tr>
<tr>
<td>• Bloody, black or tarry stools</td>
<td>• Increased thirst</td>
</tr>
<tr>
<td>• Cough or hoarseness</td>
<td>• Increased urination</td>
</tr>
<tr>
<td>• Darkening of the skin</td>
<td>• Loss of appetite</td>
</tr>
<tr>
<td>• Decrease in height</td>
<td>• Loss of sexual desire or ability</td>
</tr>
<tr>
<td>• Decreased vision</td>
<td>• Lower back or side pain</td>
</tr>
<tr>
<td>• Diarrhea</td>
<td>• Menstrual irregularities</td>
</tr>
<tr>
<td>• Dry mouth</td>
<td>• Muscle pain or tenderness</td>
</tr>
<tr>
<td>• Eye pain</td>
<td>• Muscle wasting or weakness</td>
</tr>
<tr>
<td>• Eye tearing</td>
<td>• Nausea</td>
</tr>
<tr>
<td>• Facial hair growth in females</td>
<td>• Pain in the back, ribs, arms or legs</td>
</tr>
<tr>
<td>• Fainting</td>
<td>• Painful or difficult urination</td>
</tr>
<tr>
<td>• Fever or chills</td>
<td>• Skin rash</td>
</tr>
<tr>
<td>• Flushed, dry skin</td>
<td>• Sweating</td>
</tr>
<tr>
<td>• Fruit-like breath odor</td>
<td>• Trouble healing</td>
</tr>
<tr>
<td>• Full or round face, neck or trunk</td>
<td>• Unexplained weight loss</td>
</tr>
<tr>
<td>• Heartburn or indigestion (severe and continuous)</td>
<td>• Unusual tiredness or weakness</td>
</tr>
<tr>
<td>• Increased hunger</td>
<td>• Vision changes</td>
</tr>
<tr>
<td>• Irritability</td>
<td>• Vomiting</td>
</tr>
<tr>
<td>• Mood changes</td>
<td>• Vomiting of material that looks like coffee grounds</td>
</tr>
</tbody>
</table>

**MICHELLE GREER, RN**

IgCN, is senior vice president of sales at Nufactor, a Specialty Infusion Company.
**MEDICINES**

**Shelf Life of Octapharma’s Cutaquig 16.5% Extended**

The U.S. Food and Drug Administration (FDA) has extended the expiration date of 42 existing lots of Cutaquig (immune globulin, subcutaneous [human]-hipp, 16.5% solution) that are currently in the distribution chain. The decision extends the shelf life of all future lots of Cutaquig from 24 months to 36 months when stored at 2 degrees Celsius to 8 degrees Celsius (36 degrees Fahrenheit to 46 degrees Fahrenheit). The six-month shelf life of Cutaquig stored at room temperature up to +25 degrees Celsius (77 degrees Fahrenheit) remains unchanged. Future lots of Cutaquig will be labeled according to the new dating period.

“The FDA extension is great news for adult primary immune disease patients concerned about the available supply of immunoglobulin products,” said Octapharma USA President Fleming Nielsen. “As the supply of immunoglobulin products faces challenges in the near future, the longer shelf life of Cutaquig is an important consideration. Octapharma has increased its production of immunoglobulin products by more than 45 percent over the last year so we have strong supply to meet patient needs.”

**RESEARCH**

**Neutropenia More Prevalent Than Previously Found in Children PI Patients**

In a study conducted to determine the overall frequency and severity of neutropenia in children diagnosed with a primary immunodeficiency disorder (PI), researchers found it is more prevalent than previously found. In the study, neutropenia data and demographic/clinical information were collected from the USIDNET registry from 1,145 patients younger than 21 years of age. In all broad PI categories, as well as in almost all individual PIs, there was a greater than 10 percent occurrence rate of neutropenia. In African American pediatric PI patients, neutropenia frequency was greater than in white or Asian patients. The degree of neutropenia in pediatric PI patients was not correlated with mortality. According to the researchers, although the incidence of PI in patients presenting with neutropenia was not evaluated in the study, the probability of a PI disorder in patients with idiopathic neutropenia should be considered.

**RESEARCH**

**New Questionnaire Reliably Identifies the Burden of IG Treatment for PI Patients**

A study shows a new patient-generated questionnaire known as the IgBoT-35 appears to be reliable for helping to identify more individualized and preferred therapies for primary immunodeficiency disease (PI) patients when used in clinical practice.

In the study, 472 PI patients in 10 countries (nine in Europe and one in Canada) completed the questionnaire, 395 of whom were being treated with intravenous immune globulin (IVIG) (32 percent) and subcutaneous IG (SCIG) (67 percent). The questionnaire contained 34 items across eight domains of treatment burden (time, organization and planning, leisure and social, interpersonal relationships, employment and education, travel, consequences of treatment and emotional) and an additional IG treatment burden global question at the end. The study found treatment burden was lower than anticipated across the different treatment routes and countries, although overall was more burdensome for patients undergoing IVIG compared with SCIG treatment.

A new survey with a sample of U.S. patients is currently being undertaken to further establish the validity and conceptual model. According to the researchers, PI patient preferences are important to guide treatment decisions and to ensure they receive the right treatment at the right time.
In the News

**LEGISLATION**

**Congress Extends IVIG Demonstration Project Through 2023**

On Dec. 21, 2020, Congress passed the Consolidated Appropriations Act, 2021, which included a section that extends the IVIG [intravenous immune globulin] In-Home Demonstration Project (which began in 2003 and was scheduled to end Dec. 31, 2020) through the end of 2023.

With the signing of this bill, participating patients will continue to receive their benefits for at least three more years. No re-enrollment is required for those already participating in the project. It also requires the Centers for Medicare and Medicaid Services to provide a report to Congress on the outcomes of the project within two years of passage of this legislation so the demonstration can be analyzed before it expires again in 2023. And, it expands the cap on beneficiaries from 4,000 to 6,500 to ensure everyone with primary immunodeficiency (PI) who is eligible may enroll.

In addition to safeguarding in-home IVIG access for Medicare beneficiaries with PI, the package includes language from the Preserving Patient Access to Home Infusions Act, ensuring Medicare beneficiaries with PI will have continued access to all subcutaneous IG products and services. This removes a barrier to coverage for IG therapies designated as a self-administered drug in local coverage determinations by a Medicare Administrative Contractor.

For more information, go to med/noridianmedicare.com/web/ivig.


**RESEARCH**

**UK PI Patients Experience Greater Morbidity and Mortality with COVID-19 Infection**

A study conducted in the United Kingdom reveals patients with primary immunodeficiency (PI) or symptomatic secondary immunodeficiency (SI) display greater morbidity and mortality from COVID-19 infection.

At the start of the COVID-19 pandemic, the United Kingdom Primary Immunodeficiency Network established a registry of cases to collate the nationwide outcomes of COVID-19 in patients with PI or SI to determine risk factors associated with morbidity and mortality from the virus. By July 1, 2020, 100 patients had been enrolled in the study, 60 of whom had PI, seven of whom had inborn errors of immunity, including autoinflammatory diseases and C1 inhibitor deficiency, and 33 of whom had symptomatic secondary immunodeficiency. In individuals with PI, 53.3 percent were hospitalized, the infection fatality rate was 20 percent, the case fatality rate was 31.6 percent and the inpatient mortality rate was 37.5 percent. Individuals with SI had worse outcomes than those with PI, with 75.8 percent hospitalized, an infection fatality rate of 33.3 percent, a case fatality rate of 39.2 percent and inpatient mortality of 44 percent.

The researchers concluded this increased risk must be reflected in public health guidelines to adequately protect vulnerable patients from exposure to the virus.

Hizentra®
Immune Globulin Subcutaneous (Human) 20% Liquid

My Life,
My Way
With
Hizentra

Hizentra is an Ig* therapy that provides proven PI protection with the convenience of self-administration, so you can focus on everyday living

*Ig=immunoglobulin

Important Safety Information

Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid, is a prescription medicine used to treat:

- Primary immune deficiency (PI) in patients 2 years and older
- Chronic inflammatory demyelinating polyneuropathy (CIDP) in adults

WARNING: Thrombosis (blood clots) can occur with immune globulin products, including Hizentra. Risk factors can include: advanced age, prolonged immobilization, a history of blood clotting or hyperviscosity (blood thickness), use of estrogens, installed vascular catheters, and cardiovascular risk factors.

If you are at high risk of blood clots, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor for signs of clotting events and hyperviscosity. Always drink sufficient fluids before infusing Hizentra.

See your doctor for a full explanation, and the full prescribing information for complete boxed warning.

Treatment with Hizentra might not be possible if your doctor determines you have hyperprolinemia (too much proline in the blood), or are IgA-deficient with antibodies to IgA and a history of hypersensitivity. Tell your doctor if you have previously had a severe allergic reaction (including anaphylaxis) to the administration of human immune globulin. Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Inform your doctor of any medications you are taking, as well as any medical conditions you may have had, especially if you have had recent therapy with Hizentra, as effectiveness of the vaccine could be compromised.

Before receiving any vaccine, tell immunizing physician if you have effect that bothers you or does not go away.

The most common side effects in the clinical trials for Hizentra were:

- Redness, swelling, itching, and/or bruising at the infusion site;
- Headache; chest, joint, or back pain;
- Diarrhea; tiredness; cough;
- Rash; itching; fever, nausea, and vomiting. These are not the only side effects possible.

Tell your doctor about any side effects you get and any that bother you, especially:

- Pain and/or swelling or discoloration of an arm or leg, unexplained chest pains or breathing trouble; fever over 100°F (possible signs of a kidney problem);
- Brown or red urine; rapid heart rate; yellowing of the skin or eyes; bad headache with nausea; vomiting; stiff neck; fever; and shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness/weakness on one side of the body (possible signs of a blood clot).
- Reduced urination, sudden weight gain, or swelling in your legs (possible signs of heart failure).

Please see Brief Summary of full Prescribing Information on reverse.
Simplify your infusions with the first and only Ig prefilled syringes—only from Hizentra

Simple, convenient, and ready to use, so you can get back to everyday living

Choose when and where you infuse
Self-administration with Hizentra means you and your doctor can decide when and where you infuse. Convenient dosing options (from daily to once every 2 weeks) mean you won’t have to adjust or cancel your plans due to IV infusion appointments.

No more IV infusions
IV infusions can be challenging for people who have hard-to-find or damaged veins. Hizentra allows you to infuse just under the skin, not into a vein, after training from your doctor.

Proven Safety
Hizentra has an established safety profile and demonstrated tolerability. In clinical trials, the most common side effects were redness, swelling, itching, and/or bruising at the infusion site; headache; chest, joint, or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible.

Visit www.HizentraPFS.com or ask your doctor about Hizentra prefilled syringes.

Immediately report to your physician any of the following symptoms, which could be signs of serious adverse reactions to Hizentra:
- Reduced urination, sudden weight gain, or swelling in your legs (possible signs of a kidney problem).
- Pain and/or swelling or discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness/weakness on one side of the body (possible signs of a blood clot).
- Bad headache with nausea; vomiting; stiff neck; fever; and sensitivity to light (possible signs of meningitis).
- Brown or red urine; rapid heart rate; yellowing of the skin or eyes; chest pains or breathing trouble; fever over 100°F (possible symptoms of other conditions that require prompt treatment).

Hizentra is made from human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

The most common side effects in the clinical trials for Hizentra include redness, swelling, itching, and/or bruising at the infusion site; headache; chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible. Tell your doctor about any side effect that bothers you or does not go away.

Before receiving any vaccine, tell immunizing physician if you have had recent therapy with Hizentra, as effectiveness of the vaccine could be compromised.

Please see full prescribing information for Hizentra, including boxed warning and the patient product information, available at Hizentra.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

You can also report side effects to CSL Behring’s Pharmacovigilance Department at 1-866-915-6958.

Biotherapies for Life*  CSL Behring
Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid
Initial US Approval: 2010

BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use Hizentra safely and effectively. Please see full prescribing information for Hizentra, which has a section with information directed specifically to patients.

What is HIZENTRA?
HIZENTRA is a prescription medicine used to treat primary immune deficiency (PI) and chronic inflammatory demyelinating polyneuropathy (CIDP). Infuse HIZENTRA only after you have been trained by your doctor or healthcare professional. HIZENTRA is to be infused under your skin only. DO NOT inject HIZENTRA into a blood vessel (vein or artery).

Who should NOT take HIZENTRA?
Do not take HIZENTRA if you have too much proline in your blood (called “hyperprolinemia”) or if you have had reactions to polysorbate 80. Tell your doctor if you have had a serious reaction to other immune globulin medicines or have been told that you have a deficiency of the immunoglobulin called IgA.

Tell your doctor if you have a history of heart or blood vessel disease or blood clots, have thick blood, or have been immobile for some time. These things may increase your risk of having a blood clot after using HIZENTRA. Also tell your doctor what drugs you are using, as some drugs, such as those that contain the hormone estrogen (for example, birth control pills), may increase your risk of developing a blood clot.

What are possible side effects of HIZENTRA?
The most common side effects with HIZENTRA are:

- Redness, swelling, itching, and/or bruising at the infusion site
- Headache/migraine
- Nausea and/or vomiting
- Pain (including pain in the chest, back, joints, arms, legs)
- Fatigue
- Diarrhea
- Stomach ache/bloating
- Cough, cold or flu symptoms
- Rash (including hives)

- Itching
- Fever and/or chills
- Shortness of breath
- Dizziness
- Fall
- Runny or stuffy nose

Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Tell your doctor right away if you have any of the following symptoms. They could be signs of a serious problem.

- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain and/or swelling of an arm or leg with warmth over the affected area, discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness or weakness on one side of the body. These could be signs of a blood clot.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of a brain swelling called meningitis.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a blood problem.
- Chest pains or trouble breathing.
- Fever over 100°F. This could be a sign of an infection.

Tell your doctor about any side effects that concern you. You can ask your doctor to give you more information that is available to healthcare professionals.

Please see full prescribing information, including full boxed warning and FDA-approved patient product information. For more information, visit Hizentra.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

You can also report side effects to CSL Behring’s Pharmacovigilance Department at 1-866-915-6958.

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**RESEARCH**

**Study Finds SCIG and IVIG Are Effective as Maintenance Therapy for MG**

A study that compared the effects of long-term intravenous immune globulin (IVIG) and subcutaneous IG (SCIG) maintenance therapy in adults with generalized myasthenia gravis (gMG) showed reduced impairments, decreased use of other medications and improved overall health status. In addition, 90 percent of study subjects preferred SCIG after first being treated with IVIG.

The study assessed 34 patients between the ages of 24 years and 81 years (mean age 58.9) with a disease duration between three and 35 years who were treated with IG for at least six months between January 2015 and January 2020 for acute exacerbations, or myasthenic crisis (a severe weakening of muscles resulting in respiratory failure). All of the patients had also been treated with immunosuppressive medicine. Of the 34 patients, three received SCIG infusions only, and one underwent only IVIG infusions. For the remaining 30 patients, who were treated with IVIG followed by SCIG, the mean duration of IVIG therapy was 21.8 months, and the mean duration of SCIG treatment was 19.5 months. Those patients were treated with 1 gram per kilogram per day of IVIG and-scig-effective-as-maintenance-therapy-in-mg-study-/finds.

“Offering SCIG therapy is a no-brainer because our patients prefer it,” the study’s lead author, S. Bryson, M.D., said. “It is associated with a decrease in the use of other medications and is well tolerated.”

Results showed a significant reduction in MGII scores from a mean of 27.7 before treatment, or baseline, to 22 after IVIG. The improvements started with IVIG treatment stabilized during the SCIG period with a mean MGII score of 19.5. A patient-reported outcome called “percentage of normal” showed high scores associated with both treatments, increasing from 60.9 percent at baseline to 72.4 percent after IVIG treatment and 72.3 percent with SCIG. In turn, better scores in “percentage of normal” were linked with lower (improved) MGII scores after both treatments. Three patients achieved minimal symptoms at the end of follow-up with no weakness and no MG-related impairments that affected daily activities. Their “percentage of normal” score was 95 percent. The use of immunosuppressants was also lowered with chronic IG treatment.

“Although we have conventional treatments, they are not all applicable to what is a very difficult patient group. The majority of patients with ITP are male over 60 [years] who have other comorbidities. So, treatments that are likely to be associated with thrombosis and venous thromboembolism need to be avoided. Therefore, there is clearly an unmet need in this particular population,” said Adrian C. Newland, CBE, FRCP, FRCPath, professor of hematology at University of London. “Although we have conventional treatments, they are not all applicable to what is a very difficult patient group. The majority of patients with ITP are male over 60 [years] who have other comorbidities. So, treatments that are likely to be associated with thrombosis and venous thromboembolism need to be avoided. Therefore, there is clearly an unmet need in this particular population.”

**MEDICINES**

**Study Shows Efgartigimod Is Safe and Effective for Treating ITP**

Phase II study results show efgartigimod, a neonatal Fc receptor antagonist, was well-tolerated and effective in patients with primary immune thrombocytopenia (ITP), a bleeding disorder characterized by a low platelet count that is difficult to treat. In the study, 38 ITP patients who were relapsed or refractory to conventional treatments were randomly assigned to receive 5 mg of efgartigimod, 10 mg of efgartigimod or placebo. Overall, treatment was well-tolerated with no significant treatment-related adverse events and was associated with a reduction in bleeding that occurred in conjunction with platelet increments. An open-label extension analysis showed the 10 mg dose was effective in patients who did not adequately respond to the 5 mg dose or placebo.

There is clearly an unmet need in this particular population,” said Adrian C. Newland, CBE, FRCP, FRCPath, professor of hematology at University of London. “Although we have conventional treatments, they are not all applicable to what is a very difficult patient group. The majority of patients with ITP are male over 60 [years] who have other comorbidities. So, treatments that are likely to be associated with thrombosis and venous thromboembolism need to be avoided. Therefore, there is clearly an unmet need in this particular population.”

SCIG with Recombinant Human Hyaluronidase Is Safe and Preferred vs. IVIG by Some Multifocal Motor Neuropathy Patients

A team of Dutch investigators enrolled 18 multifocal motor neuropathy (MMN) patients on intravenous immune globulin (IVIG) treatment in a prospective open-label study to evaluate the comparative safety of treatment with 10% human immune globulin whose subcutaneous administration is facilitated with recombinant human hyaluronidase (fSCIG) (HyQvia).

Patients remained on IVIG treatment for three visits over 12 weeks, followed by a second 36-week study phase during which they received fSCIG treatment at an equivalent dose and frequency for three more visits, followed by self-administration of fSCIG at home. Outcome measures included safety, muscle strength, disability and treatment satisfaction.

Switching to fSCIG reduced the systemic adverse event rate (IVIG 11.6 vs. fSCIG 5.0 adverse events per person-year; p < 0.02), and increased the number of local injection site reactions (IVIG 0 vs. fSCIG 3.3 local reactions per person-year; p < 0.01). Overall, no significant difference in muscle strength or disability was found between IVIG and fSCIG.

Citing improved independence and treatment scheduling flexibility, eight of the 17 patients (47 percent) who completed the study perceived fSCIG as optimal treatment, and all eight continued with fSCIG following study completion.

The investigators concluded fSCIG is a safe alternative for patients with MMN on IVIG treatment. Additionally, “fSCIG could be a favorable option in patients who prefer self-treatment and more independence, and in patients who experience systemic adverse events on IVIG or have difficult intravenous access.”

The researchers found patients who had mild disease (QMG5 below 10.5) and high electrical signal decrement values (of 10 percent or above) at an initial evaluation were 6.7 to 21.5 times more likely to be treated with IVIG and plasmapheresis. In contrast, higher electrical signal fluctuations were associated with CellCept treatment.

According to the researchers, electrophysiological decrement at an initial evaluation may be useful in assessing people with MG and in predicting their long-term outcomes. However, additional research in larger patient groups is necessary.

Patients with Mild MG and Poorer Nerve Cell Response More Likely to Receive IVIG Treatment

An international research team that explored the extent to which electrophysiological abnormalities could impact treatment regimens in myasthenia gravis (MG) patients found those with mild MG with poorer nerve cell response in initial diagnostic tests are more likely to progress to more aggressive therapy regimens than those with better nerve responses. An electrophysiological test conducted to assess the ability of nerve cells to conduct and transmit the electrical pulses needed to stimulate muscle cells is commonly given to individuals with MG.

In the study, researchers reviewed the clinical records of 87 individuals suspected of having MG and referred to the Prosserman Family Neuromuscular Clinic at the University Health Network in Toronto, Canada, between June 2012 and December 2015. Patients were followed for a mean period of 2.6 years and were prescribed common treatments for MG, which included Mestinon (pyridostigmine), prednisone, azathioprine, CellCept (mycophenolate), intravenous immune globulin (IVIG) and plasma exchange.

Patients who showed greater fluctuations in the electrical signal at the neuromuscular junction and lower electrical signals (reduced by 20 percent or more) at the first visit were more frequently positive for autoantibodies and had generalized disease. These people were also classified as having more severe disease and a higher quantitative (above 10.5) MG score (QMG5) at baseline compared to those with better electrophysiological test results.

The researchers found patients who had mild disease (QMG5 below 10.5) and high electrical signal decrement values (of 10 percent or above) at an initial evaluation were 6.7 to 21.5 times more likely to be treated with IVIG and plasmapheresis. In contrast, higher electrical signal fluctuations were associated with CellCept treatment.

According to the researchers, electrophysiological decrement at an initial evaluation may be useful in assessing people with MG and in predicting their long-term outcomes. However, additional research in larger patient groups is necessary.
Download the *IG Living* eBook today—now available for iPad, Nook and Kindle!

“You can lament what is lost to you, whether it’s opportunity, a person or your health, but clinging to anger is no way to experience life.” — Rebecca Zook in “Life Lessons,” excerpted from *Chronic Inspiration.*

Download a daily dose of inspiration with this heartfelt compilation of writings on life with chronic illness. From coping strategies and parenting tips to “from the trenches” advice on dealing with family and friends who simply don’t get it, these personal stories are sure to uplift, challenge and inspire. Honest and candid, Chronic Inspiration: Heartfelt Perspectives on Life with Chronic Illness gives voice to those who refuse to let their diagnosis define who they are or what they can accomplish.

“For the patient community, this was invaluable. When I downloaded it, I knew this would be something I would refer to over and over again.”

— Jenny Gardner

*Chronic Inspiration* can be purchased on iTunes, Amazon and Barnes and Noble.com
Fighting the Loneliness of Chronic Illness

Patients can overcome loneliness by developing new relationships, hobbies and interests, but it takes practice, effort and creativity.

By Meredith Whitmore

IT IS SAFE to say this past year has been difficult for the entire globe. For many, the pandemic’s extended lockdown has resulted in loneliness. The problem is humans are hardwired to be naturally social. And those who suffer from chronic illness that already limits regular social interaction are feeling a deeper sense of loneliness during quarantine.

Loneliness is a health risk. Although unpleasant to hear, a few sobering facts illustrate the problems with loneliness, as well as the importance of tackling them: Loneliness is likely to increase one’s risk of death by 26 percent. Loneliness, living alone and poor social connections are as bad for one’s health as smoking 15 cigarettes a day and is more detrimental than obesity. Loneliness and social isolation are associated with an increased risk of developing coronary heart disease and stroke, an increased risk of high blood pressure, early mortality when coupled with severe depression and a risk factor for depression in later life. Loneliness and social isolation also put individuals at greater risk of cognitive decline and dementia. Studies have shown people who have high levels of chronic illness become lonelier over time, while
those with lower levels of chronic illness do not. Indeed, for older adults, having high levels of chronic illness presents a significant risk factor for becoming lonely.8

So, what can be done to help people overcome the loneliness of chronic illness? Actually, quite a bit. Here are some useful tips — many of which are evidenced-based — to help patients better cope with compounded layers of loneliness and illness during this extraordinary time.

Learn Something New

Keep your mind agile and active. Join an online class, or if you have the ability and means, take an in-person class or workshop to learn about something that interests you; you might even make new contacts in the process. There’s something for everyone, from cooking, books, movies, school subjects, spirituality, exercise and sports, and many are often free. YouTube, The Great Courses and Khan Academy, among many others, are excellent online educational resources that allow people to learn everything from the tango to trigonometry. MIT OpenCourseWare, as well as countless other universities around the world, also offer free online courses. Most of these courses allow access to a syllabus, course calendar, assignments and study materials (although there may be a fee in some cases). Best of all, you can usually work at your own pace.

Reframe Your Thinking

Create cognitive flexibility and other mental health skills to better cope with illness and the loneliness it can cause. Many different types of therapy can alleviate loneliness and pain, but cognitive behavioral therapy (CBT) research backs its ability to alter the way people view their situations to find more balance and positivity. “CBT can change the thoughts, emotions and behaviors related to pain, improve coping strategies and put the discomfort in a better context,” says Joseph Hullett, MD, board certified psychiatrist and senior medical director for OptumHealth Behavioral Solutions in Golden Valley, Minn.9

CBT is based on the belief that people can modify their perceptions and responses to everything they experience in their lives, helping them to balance negative thoughts and behaviors with more helpful and realistic ones. By examining and replacing negative thinking patterns, people can change the way they view pain and loneliness — even if their pain and loneliness remain. “The perception of pain is in your brain,” Dr. Hullett explains, “so you can affect physical pain by addressing thoughts and behaviors that fuel it.” CBT can even alter the body’s physical responses, causing neurochemicals such as norepinephrine and serotonin to be released. “CBT reduces the [stressful] arousal that impacts these chemicals,” adds Dr. Hullett. This, in effect, may make the body’s natural pain relief response more powerful.

To access CBT’s healing tools, contact a therapist who specializes in it and chronic illness. There are also helpful workbooks that can be self-guided journeys toward better thinking about difficult problems such as loneliness and illness. The CBT Toolbox: A Workbook for Clients and Clinicians by Jeff Riggenbach and Feeling Good by David Burns are two classics. Although these books do not focus specifically on chronic illness, they are a foundation for handling anxiety, depression and other difficult emotions that often accompany loneliness and pain.

Create cognitive flexibility and other mental health skills to better cope with illness and the loneliness it can cause.

Be Grateful

Feeling and expressing gratitude for what we have is scientifically proven to help the brain cope with pain, loneliness, bad moods and other troubling circumstances. It can also improve sleep, reduce pain, anxiety and depression, and help to regulate stress.10 The next time you’re tempted to complain, feel bitter or see things in an otherwise negative light, try counting your proverbial blessings instead. Doing so can literally help your mind and body.

Heidi Gray, a freelance writer in Northeastern Oregon, suffers from a rare heart condition that often leaves her feeling fragile, tired and cooped up at home. Still, she embodies gratitude and says to all who might be in her boat: “I am serious when I say I think a large part of dealing with the loneliness of attitude. I’ve always been a glass-half-full person, but if you can find one positive thing to do a day, it really helps. When I get down, I try to get out of my own head,
send an encouraging note to a friend or pray for someone I know who is struggling. And self-care is important, too. I try to get up every morning, make my bed and get dressed. Even if I just lie back down on top of the covers to rest, at least I started well. And if the kids’ friends come over, at least I’m dressed to say hi!"

See a Buddy Virtually

In these days of social distancing and global health concerns, a new industry is booming: Zoom. It’s not only Zoom, though. Google Meet, Google Hangouts, Marco Polo, Microsoft Teams, Facetime and other technological tools are designed to bring people together from afar via their electronic devices. And, more and more clubs, groups and classes are using these platforms to connect face-to-face as well.

Pen Pals Aren’t Old-Fashioned Anymore

Pen pals are currently in vogue. Why be lonely during times of health problems and isolation when you have the ability to write to new friends and receive their letters as well? Developing a new relationship through writing and other forms of communication — doing so cautiously, of course, since people are not always who they seem from afar — is a savvy, fun way to socially distance and get to know others. Sites such as Compatipal, International Geek Girl Pen Pals Club, Conversation Exchange, PenPal World, Postcrossing, Worldwide Snail Mail Pen Pals and Wanderful all offer a variety of people, cultures, languages and ways to connect with others through hobbies, areas of study and other interests.

Smartphones for Connection

They get a bad rap, but smartphones aren’t always alienating when used in relationships. The same goes for laptops and tablets. If you feel lonely and miss family or friends, try sending them an encouraging message through social media, text or a real-time phone call. Follow them on social media while posting your own uplifting entries. Or, join a social media group for support, whether the group focuses on illness or interests. There are all kinds of options for those who are willing to explore resources.

Volunteer

This option might seem unlikely at first, since volunteering sounds like it requires at least some travel and a lot of energy. But these days, it’s possible to be involved with a variety of organizations in the comfort of your own home and still make your region, and even the world, a better place. Organizations such as Project Gutenberg, LibriVox, DoSomething.org, Amnesty International, Crisis Text Line, Translators Without Borders (for the bilingual and polyglots) and Catchafire offer tasks that volunteers can do from home. It’s worth your time to look for these or similar places offering work that can help you feel connected and productive. Reaching out to people or doing work that improves someone else’s life is the quintessential way to take ourselves out of our own problems and use our skills to meet others’ needs.

Take Photos

There’s no need for expensive photography equipment because your smartphone, or a frugal digital camera, offers a way to see the everyday world from a new perspective. Try focusing on even the mundane from a different angle. See books, houseplants, pets, flowers, weeds and virtually anything else with an artist’s eye. Imagine what your home would look like from an insect’s perspective. What would a sunrise or sunset look like from one of your windows? And have you ever looked at your patterned dishes up close in just the perfect light or shadow? Free online photo editing software is available to add some special effects to your fun creations. Share your work with a hobby group or friends if you like.
Online Counseling
Online counseling, whether through an exclusively online service such as BetterHelp or TalkSpace, or a private practice counselor who uses telehealth, can be a lifesaver, quite literally. Even an online peer support group such as 7 Cups of Tea can offer encouragement, virtual companionship and great ideas to help you cope and thrive. Therapists can help with chronic pain while showing people ways to navigate loneliness as well.

Travel in Your Own Home
Today, a number of sightseeing adventures are available online. Enjoy the northern lights, Israel, the Louvre and other famous museums, Disney World and even the Great Wall of China. Facebook and other social media platforms often offer ads for such “excursions,” or simply search virtual tours online to find what might interest you.

Find a Group, Support or Otherwise
Meetup.com offers something for just about everyone, depending on location, for in-person and virtual activities such as book clubs, hiking, wine tasting, dining and anything else you can imagine. Meetup even has groups for those with chronic illnesses. And, it’s fairly simple to find support through groups such as the National Fibromyalgia & Chronic Pain Association, The Mighty, MyChronicPainTeam and others that can be found with some search engine research. Finding online support that might lead to in-person companionship is only a click or phone call away.

Welcome a Pet
This might sound overwhelming to some, but it doesn’t have to be. Home delivery resources such as Chewy allow pet supplies to arrive at your door, sparing you a tiring trip to the store. And more petite animals such as small dog breeds, cats and rabbits can be litter box trained fairly easily. A pet offers comfort, humor, companionship and unconditional love that often helps reduce loneliness. There are also online and in-person support and education groups that focus on pet ownership.

No One Is an Island
There are other ways to reduce loneliness as well, but these are a great start. May you find some comfort and new activities and relationships in 2021! No one is an island, including you. The next time you feel the pangs of loneliness, take heart. Others have come through it, even while experiencing chronic illness. Of course, loneliness cannot be sugar-coated, and simply trying something new will not make it magically go away. But, those feelings of loneliness can be better managed and greatly improved with practice, effort and creativity. It can take time to develop new relationships, hobbies or interests depending on the activity, but it can be done — and it can be done very well even during a global pandemic.

MEREDITH WHITMORE is an English professor and freelance journalist in the Northwest.

References
This Dog’s for You:
Benefits of Assistance Dogs

The physical, emotional and medical support dogs can provide patients can be a lifeline, but due diligence is necessary to ensure the safety of the dogs, too.

By Amy Scanlin, MS

WITH THE TUG of a leash, a little girl and her dog are on their way, beginning a new life together — one her parents hope, as they anxiously watch their first tentative steps, will open a new world of possibilities. A man, confusion mounting, feels the nudge of his dog, alerting him to an oncoming seizure. A medical alert button is pressed and minutes later, lifesaving help arrives at his door. While such benefits of a loving companion animal have long been known, assistance dogs also play crucial roles in many people’s quality of life. From the earliest evidence of a dog leading the blind discovered in a Pompeii frieze to the 1920s when a seeing eye dog and his handler inspired Morris Frank and Dorothy Harrison Eustis to co-found The Seeing Eye that provides dogs to the visually impaired, dogs have had roles well beyond loving companion animals.

Today, assistance dogs are largely trained by hundreds of volunteer organizations that place the best of the best with individuals who benefit from their support. These dogs assist with everyday tasks that are difficult, if not impossible, for their partners to perform. For instance, they provide physical support such as opening doors, turning on light switches and carrying items. They provide balance and mobility assistance to help their partners maintain independence. They can raise the alarm for the onset of a diabetic, epileptic or cardiac event and summon help or offer stimulation. They can lower stress levels, provide deep pressure support for those with tremors, offer companionship, and help to improve verbal and nonverbal communication.
The Nose Knows

A dog’s olfactory senses are 100,000 times more precise than a human’s. According to Parkinson’s Alert Dogs, their sense of smell is so acute (they have 300 million scent receptors in their noses, 295,000 more than humans) that they can detect a teaspoon of sugar in millions of gallons of water. Forty percent of a canine brain is dedicated to analyzing smells, enabling dogs to isolate specific odors from scents. So where humans can smell a loaf of bread baking, dogs can tell whether the flour used was bleached and how. With noses that can inhale and exhale simultaneously, they are able to sniff and breathe at the same time.

These amazing detection capabilities can make dogs incredibly advantageous in medical settings. Whether it is Cliff the beagle’s 97 percent accuracy for screening a ward of patients for the bacteria Clostridium difficile via stool samples (compared to 92.7 percent reported accuracy for real-time PCR diagnostic methods) or Stewie, the Australian shepherd and part of the In Situ Foundation (which created the first medical protocol for the selection, training and handling of a medical scent detection dog), detecting early stage lung, ovarian and breast cancer, studies are looking at how a dog’s nose may benefit the medical community.

Assistance dogs are so adept with scent detection that the University of Pennsylvania’s School of Veterinary Medicine’s Working Dog Center, according to postdoctoral research fellow Jennifer Essler, PhD, hasn’t yet been able to identify a threshold that their trained dogs can’t meet, and they’ve been trying! “These dogs are incredible,” she says of their cadre. Using a Universal Detector Calibrant with varying strengths, the center’s dogs, which are used exclusively in research and have long genetic histories of being super smellers, are trained to identify whatever the laboratory is researching, from cancer to COVID-19. Their noses are so precise that, even as smaller and smaller test sizes are used, the dogs are able to seek and find the scent before them. The laboratory’s goal is in part to create an electronic nose, like a blood test, so they continue to ask: Can dogs do this and, if so, how?

Service, Work and Support

Dogs can have measurable and immeasurable positive impacts on those with both emotional and physical needs. In fact, a Purdue University College of Veterinary Medicine study found not only did people who had received a service dog have better emotional and social health than those who were on a wait list, a study at the University of California, Los Angeles, showed a 12-minute visit with a dog can lead to improved heart and lung function among hospitalized heart failure patients, with benefits exceeding those from a visit by a human or from being left alone. Dogs are known to improve their partners’ independence, social relationships, self-esteem and life satisfaction. They also help to decrease stress and loneliness, benefits voiced by owners of assistance animals.

Dogs come in all shapes and sizes and can assist with all kinds of mobility and medical alerts. The nomenclature “service dogs” is often confused with “therapy dogs,” “emotional support dogs” and other terms. The U.S. Department of Justice uses “service dogs” or “service animals” as the inclusive term, but internationally the term “assistance dogs” is often heard.

There are three types of assistance dogs providing service: guide dogs for the visually impaired, hearing dogs for the hearing impaired and service dogs for those requiring assistance other than sight and sound. There is no federal system in the U.S. that oversees registration, qualification or training of assistance dogs; however, the Americans with Disabilities Act (ADA) does mandate that dogs that provide assistance or service have full public access rights, enabling them to be brought into restaurants, stores, libraries and other public spaces and to be exempted from pet fees for travel with their partners. Per the ADA, disability is defined as a “physical, sensory, psychiatric, intellectual or other mental disability,” and the work of one’s assistance dog must be directly related to his or her needs. On the other hand, emotional support dogs are not considered assistance or service dogs under the ADA because they are not trained to specifically assist their partners.
In contrast, working dogs include those with a particularly keen sense of smell that detect diseases such as cancer, the presence of allergens or onset of medical events. Military, police and search and rescue dogs also fall into the working dog category. Regarding a dog’s diagnostic capabilities, questions remain about the feasibility of widespread use in part due to reproducibility issues, both with the same dog and with other breeds, and regulatory uncertainty. However, as exploration of this line of study widens, it is conceivable dogs could become a cost-effective, sustainable alternative to conventional diagnostic testing with significantly less medical waste produced from test kits.

Therapy dogs work side by side with their owners providing comfort in hospital and hospice settings, nursing homes, school reading programs, etc. Like assistance dogs, there are no uniform state or national regulations or certifications for therapy dogs, although there are organizations that offer training and certifications, many of which follow guidelines set forth by the American Kennel Club’s Canine Good Citizen program.

For a dog to be considered an emotional support dog, a patient must have a prescription from a mental health professional for a diagnosed psychological or emotional disorder. This letter does not allow for unlimited access to public spaces that is offered to assistance dogs. In fact, after more than a year of lobbying by U.S. airlines, emotional support animals (ESA) may be departing the passenger cabin. The U.S. Department of Transportation announced it is revising the Air Carrier Access Act on the transportation of service animals by air “to ensure a safe and accessible air transportation system.”

Trained service animals like guide dogs for the blind will be permitted; ESA animals will not. Instead, they will be treated as pets, and their owners will need to pay pet travel fees.

This Dog’s for Me

Assistance dogs open doors for people, figuratively and literally. They can help to interrupt self-harming behaviors and ease integration of their partner into the community. Studies demonstrate people are more likely to engage with those who have special needs when they have a service dog. For that reason, it is important these dogs be emotionally sturdy, easy to train and considered by the public to be friendly.

Saint Francis Service Dogs of Roanoke, Va., primarily trains Labrador and golden retrievers. “A lot of people need a dog that will pick up and carry things or bring things you need,” says Cabell Youell, executive director of Saint Francis Service Dogs. “Retrievers are a good size: strong so they can pull on a door handle or hold open a commercial door, and tall enough to turn on a light switch.” Other commonly seen service dogs are German shepherds and poodles.

Some ask why assistance animals are dogs and not other animals. As Dr. Essler explains, service or working animals are needed to do what we need, and they need to be motivated to interact with us for long periods of time. “Bears, mice and elephants also have a great sense of smell,” she jokes, “but they wouldn’t make great working animals.” Dogs have the right mix of sense of smell, are eager to interact and easy to train.

The first step in partnering with an assistance dog is speaking to a healthcare provider or social worker. Another option is to contact the not-for-profit coalition Assistance Dogs International (ADI). Being accredited and recognized by ADI is “kind of like a Good Housekeeping stamp of approval,” says Youell. Some may also choose to train their own dog or hire a trainer, which is legal under the ADA.

The process of partnering with an assistance dog is fairly universal: a comprehensive application, interviews with the applicant and his or her healthcare provider, and an in-person or remote home visit to ensure the home is a safe environment for the dog. Some organizations have fence requirements, and others limit how many other dogs can live in the home. It is important, says Youell, “to do your research and find a fit for what you need. These dogs are folding into the most intimate parts of your life. They’ll be a part of your daily routine and help you with things you struggle with. The organization needs to understand your needs and how a dog will fit into your life.”

It is also important to assess how the dog’s needs will be met such as getting sufficient exercise, an outlet for their...
energy, bathroom breaks, vet visits and high-quality food. “These dogs are solid workers and they need opportunities to be healthy,” explains Youell. It is important they are well cared for so they can take good care of their partners.

During COVID-19, Saint Francis Service Dogs has made many of its protocols virtual. “It’s had a pretty significant impact because we serve a vulnerable population, and we must be respectful of that,” says Youell. “Our mission is to help people.” Consequently, the organization is doing as much as possible through Zoom meetings, more outside training and prerecorded videos. It also believes some of these newly developed protocols will be permanent even after the pandemic ends.

Going to the Dogs

Assistance dogs offer a lifeline and can bring immeasurable benefit to people’s lives. From the care, concern and physical support of service dogs to the keenly attuned sense of working dogs, there are nearly no limits to the possibilities. Just like people, though, these animals require much care and feeding. Before individuals decide to embark on the journey of bringing an assistance dog into their lives, they must assess not only the benefits the dog will bring to them but the logistics of ensuring they can properly provide for the dog’s safety and security.

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References
I’VE KNOWN MANY weightlifters with a body chiseled like an Olympian who couldn’t jog half a lap around a track without getting winded and having to stop. I’ve also known many long-distance runners who couldn’t open a kitchen jar lid because they lacked the grip strength. We’ve probably all experienced how difficult it is to function well when we don’t give our bodies and minds enough rest and nutrition. Can someone really say they are “fit” when they pay attention to only one or two aspects of their health, and neglect the others? No. Fitness is about finding balance involving all aspects of our health.

If there’s one thing that has probably been challenged above all else during the pandemic, it’s balance. Social distancing has closed gyms; reduced the frequency of trips to the supermarket for fresh food; kept us from friends, family, work and favorite activities outside of the home; and resulted in even more screen time. When combined with the barrage of daily negative news and economical-political uncertainty, mental fitness has also been challenged for many. Home might feel more like a prison than a sanctuary.

Staying Fit at Home

Fitness is much more than physical strength and endurance; it also entails nutritious eating, proper sleep and mental/spiritual health.

By Matthew D. Hansen, DPT, MPT, BSPTS
Establishing a Routine with Proper Sleep

The first secret to maintaining balance and staying fit is establishing a routine, although flexibility and a touch of spontaneity are also important components. A good routine begins with observing an appropriate sleep schedule. Sleep is important not only for mental acuity, but to allow the body to repair itself and produce infection-fighting antibodies and protective cytokines. A good night’s rest also allows us to reset our mind and body to prepare to face another day.

By way of personal confession, this is probably the area of fitness I struggle with the most. I need to wake up by a certain time most days, but because there always seem to be more items on my to-do list than there are hours in the day, sleep is often sacrificed to work. Consequently, as the week marches on, I progressively become less productive later in the day until I eventually crash into the weekend.

Fortunately, there are things I’m already doing to improve my sleep routine. If something needs to get done before the next day, I try to eliminate unnecessary noise and other distractions. I can work well with music, but not with television. If there’s a program I really want to see, I can record it or watch it later. If I find it difficult to shut my brain off when it’s time to go to bed — which is not unusual — I’ve found certain herbal teas and soothing instrumental music help. Like all good habits, establishing a healthy sleep schedule takes discipline, but it can make a big difference.

Good Eating Habits and Adequate Hydration

To establish a good routine, you must know your body and not be afraid to be honest with yourself. For example, I’ve learned that although exercise is critical to my fitness level, if I exercise too late in the evening, it makes it more difficult for me to fall asleep. So, I’m a morning exerciser.

Understanding your nutritional needs is also essential. Most people have an idea of what it means to eat healthfully, but many people don’t. Some people have used the opportunity of being home more during the pandemic to cook and eat better, while others have increased their intake of take-out and canned or frozen foods high in preservatives. When stressed or bored, some people eat more or indulge in cravings. During the pandemic, junk food has become particularly accessible, oftentimes just feet away for those confined to home.

When I’m traveling for business or when I’m home alone on the rare occasion when the rest of the family is traveling without me, I don’t tend to eat as well. It’s not that I eat bad food, but I often don’t eat as frequently as I should. I skip meals more and don’t eat the wholesome snacks I need to keep my blood sugar level in check.

Eating healthy and drinking water and other clear liquids becomes even more important when regularly exercising. Our bodies need nutrients to function, and when we wait too long to eat between meals, thinking can become clouded, energy levels deteriorate and our bodies generally don’t function as well. If we practice poor eating habits for too long, it can also affect our metabolism and immune systems.

A good routine begins with observing an appropriate sleep schedule.

I’m someone who almost always must feel like I’m being productive, and cooking doesn’t fill that need for me unless I’m cooking for someone else. So, when I was single, cold cereal and peanut butter sandwiches were my standard go-to. Even though my carb-loaded friends of years past are still a tempting meal on the fly, as I’ve matured and become more informed, I understand I need to care for myself more thoughtfully. I still feel the need to be productive, so I now look forward to cooking with my kids when they are around, or I listen to a favorite podcast, watch an episode of a favorite program on my phone or practice a foreign language. Then the time becomes something to look forward to rather than to avoid. It’s certainly better than sitting on the couch. When fresh produce is available, I enjoy attempting new ethnic food recipes or experimenting with my own concoctions of whatever is in the fridge and needs to be used before it spoils.

Physical Exercise

Physical conditioning is usually what most people think of first when they hear the word fitness, but to be most effective, the other components of fitness already discussed (proper sleep and nutrition) are also necessary.

The COVID-19 pandemic has forced those who once relied on the local health club for exercise to find or invent other ways to keep active. It has also demonstrated that one
of the most important motivators for exercise, socialization, does not always have to be in-person to be effective. Virtually any exercise at the gym can be replicated at home, and technology has found new ways to bring friends and workout partners together. For example, peer Zoom exercise groups and virtual classes have popped up across the world. If you’re shy, and not ready to model your new yoga pants to the world, it’s easy to turn your camera off.

Although there are some amazing new exercise equipment and technology solutions for home use, their superiority compared to much simpler and less-expensive solutions is highly contestable. If you can afford it and having the latest new thing helps to motivate you, go for it! Otherwise, I recommend considering what tools you already have in the home such as a chair, bottom step, broom and gallon of water. As a home health physical therapist, I’ve created many thorough exercise routines for people using items from their pantry or utility closet.

To avoid injury or causing other harm, it’s important to have a basic understanding of the principles of exercise or, better yet, consult with someone who specializes in exercise prescription prior to initiating new activities. Therefore, the following examples of household items that can be used for different strengthening activities are not presented as part of a specifically recommended program, but rather as an illustration of how readily and inexpensively exercise can be adapted in the home setting.

**Stairs.** The stairs are one of the most versatile pieces of equipment you likely have in your home. For safety reasons, I recommend performing most activities from the bottom step while holding onto the rail. Several exercises that can be performed from the stairs include:

- **Side-dips (aka stair squats):** While standing sideways on the bottom step (perpendicular to the stair tread), squat and lower the downslope side of your body until your non-weight-bearing foot touches the floor below. Use the strength of your upslope leg to raise your body and repeat.
- **Step-ups:** With your body facing toward the staircase, step up onto the bottom step, step down and repeat.
- **Stair dips (aka triceps dips):** Sit down on the second or third step from the bottom of the staircase (the taller you are, the higher the step needs to be). Position your hands so they are next to your thighs, pushing down into the step. Walk your feet out on the floor and lift your buttocks off the step. Hinging at the elbow, lower your body as far as you can go or until your arms form a 90-degree angle.

**Chairs.** A stable chair can be just as handy as stairs when it comes to exercises, perhaps even more so, because exercises for most parts of the body can be modified for a sitting position to benefit those who need more stability or experience pain while standing on their feet. Chairs can also provide great support for standing exercises.

**Homemade weights.** There are many options when homemade weights are needed for resistance exercises. Water bottles or soup cans are perfect for light-weight, high-repetition exercises to build endurance or strengthen muscles prone to tendonitis.

When greater weight is needed, try water or milk gallons, a bottle of laundry detergent or any other plastic bottle that has a handle. Reusable canvas or plastic grocery bags can be loaded with all sorts of items to vary the weight, and then either lifted by hand or slipped by their handles over a broom, mop or PVC pipe to create an impromptu barbell. Just be careful not to let the bags slip off the barbell, or to overload the bags so that they break and spill the items onto the floor — or your feet! If you purchase PVC caps from the hardware store, you can create weights by filling segments of pipe with water, sand or gravel.

**Cushions or pillows.** Performing standing exercises while positioned on a cushion or pillow can challenge your balance and strengthen your postural muscles. To make things more difficult, try standing on one leg or closing your eyes while lightly placing one finger against a structure for support. You can also use cushions and pillows for isometric exercises (e.g., squeezing a pillow between your knees or pushing a body part against the couch to the count of five).
Cardio exercise. Many people in the gym and at home neglect the importance of cardio (aerobic) exercise, which should be performed three to five times a week based on intensity (i.e., 30 minutes of moderate activity five days a week or at least 25 minutes of vigorous activity three days a week).

Depending on where you live, getting a cardio workout at home can be challenging during the winter months, especially if there is snow on the ground and you don’t have a stationary bike or treadmill. However, it’s not impossible.

Any of the exercises already mentioned can be converted to a cardio exercise if the intensity and duration are sufficient. This may mean you need to reduce the resistance (weight) to sustain the activity long enough to have a beneficial effect on your cardio system. The key is your target heart rate, which can be tracked via a fitness tracking device or calculated as 50 percent – 85 percent of your maximum safe heart rate (i.e., 220 – your age). So, for a 60-year-old, maximum safe heart rate is 220 – 60 = 160 beats per minute (bpm). At a 50 percent exertion level, target exercise heart rate would be 80 bpm. At an 85 percent exertion level, target exercise heart rate would be 136 bpm.

Climbing stairs for aerobic exercise has already been mentioned. Based on your current fitness level, walking around the home for the allotted time, with or without an assistive device, may be sufficient. Hopefully, you’ve begun to see there are many tools within reach in your own home to help you achieve and maintain physical fitness. As you begin to safely experiment with other options, you’ll likely surprise yourself as you begin seeing otherwise ordinary household items in a completely different light.

As with the other components of fitness, the secret to your success will lie in the physical routine you create.

Mental/Spiritual Health

If you were to incorporate the other three fundamentals of fitness into your life — proper sleep, healthy eating/adequate hydration and physical exercise — you would likely already be more mentally fit than you would be otherwise because each of these components supports our mental and spiritual well-being.

I use the descriptor “spiritual” in a broader sense than the term “religious.” There are many people who are areligious who would still consider themselves to be spiritual. To me, being spiritual describes someone who is aware of — or seeking — their place in the universe, and at least acknowledges some interconnectivity among living things, which also means our actions can have an impact, for better or worse, on those around us.

The COVID-19 pandemic along with social distancing has challenged the mental health of many — if not most — of us to the nth degree. As we move forward into a future that may still look somewhat uncertain, it’s important to reestablish and maintain healthy recreational outlets and maintain our social ties with others, even when it must be virtually. Whether those experiences are planned or spontaneous, big or small, they need to be regular, and they need to be a priority in our lives.

Be healthy, be fit and be well! 🌟

MATTHEW DAVID 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.
How to Choose the Best Caregiver for Your Loved One

This step-by-step guide can help to ensure your loved one gets the appropriate care for his or her needs.

By Brenda Kimble

WHEN A LOVED one is diagnosed with a chronic illness, the automatic response is to support that person in any way possible. Running errands? Check. Keeping house? Check. Helping with treatments? Check. But taking on caregiving duties yourself might not be the right path to follow. Research shows that when a loved one becomes a caregiver, his or her own mental, physical and emotional health tend to suffer. Caregiving can also damage the personal relationship you have with your loved one. And, depending on your own situation, it might not even be a possibility.

Thankfully, there are a lot of excellent in-home caregiving options. Hiring a professional caregiver allows you to support your loved one and ensure he or she is well cared for without sacrificing other important areas of your life such as family, work and your own health.

Follow this step-by-step guide to choose the best in-home caregiver for your loved one.

Step 1. Determine the Type of Care Your Loved One Needs

One of the best reasons to opt for in-home care is it’s entirely customizable to your loved one’s situation. You can tailor the type and amount of care your loved one receives based on the chronic illness, the progression of symptoms, the treatment plan, how much assistance is required and more.

To determine exactly what your loved one needs help with, sit down for a discussion and include any other individuals who are routinely assisting. Together, make a list of broad areas and specific tasks where assistance is needed today. Here’s a list of some basic proficiencies to consider:

- Safely working through daily exercises, breathing therapy or physical rehabilitation
- Completing household chores such as cleaning and cooking
- Administering medical care and routine treatments
- Personal care such as showering, dressing and going to the bathroom
- Transportation to run errands and go to appointments
- Navigating the world, in terms of mobility or communication

As you discuss the possibilities, keep in mind the need to assess your loved one’s current physical and cognitive abilities, capability to navigate the home and outside world safely, and social life.

It might be beneficial for you to meet with the doctor (or doctors) managing your loved one’s treatment plan. They’ll be able to point out considerations you might not have considered, including how your loved one’s illness might progress and the kinds of care they’re likely to need in the coming months and years.

Step 2. Evaluate Caregiving Options to Choose the Right One for Your Loved One’s Situation

Selecting an in-home caregiver can be a daunting task since there are so many options to explore. There are two different avenues you’ll need to consider: 1) the type of caregiving your loved one needs (i.e., a registered nurse versus a health aide) and 2) the method of finding and paying for your caregiver of choice (i.e., referrals versus agency).
With a comprehensive list of your loved one’s caregiving needs, as well as a careful analysis of your current budget and funding sources, you should be able to narrow down the options outlined below.

1) What type of caregiver does your loved one need?  
*Mostly help with personal care, assistance around the house and running errands.* Nonmedical supportive care is the least expensive in-home caregiving option, but it’s also nearly always an out-of-pocket expense not covered by your loved one’s health insurance. However, the low cost comes with a caveat: They aren’t licensed, and there are few training requirements.

These caregivers are called personal care assistants (PCA). They can be hired by the hour for part- or full-time work, and their services include personal hygiene and assistance around the house, as well as housekeeping, errand-running and companionship.

*Healthcare-oriented tasks and personal care help.* There are a few types of certified healthcare providers who are trained to offer different levels of care.

The home health aide, or HHA, is the first level. These aides complete basic nursing tasks (i.e., taking vitals and monitoring your loved one’s condition), while also providing company, helping with personal hygiene and taking care of basic housekeeping tasks. An HHA tends to be covered by Medicare if their service is provided in coordination with other more-specialized care.

Beyond the HHA is the licensed nursing assistant and the certified nursing assistant, both of whom can provide a range of specialized nursing care at the direction of a registered nurse (RN).

*A variety of different kinds of help — and someone to manage it all.* Many patients with chronic illnesses have complex situations that benefit from having different caregivers to meet different needs. This is particularly true for those with progressive diseases like pulmonary fibrosis, heart disease and dementia.

RNs often function as case managers in a homecare setting. This means that in addition to delivering hands-on healthcare, they also develop care plans for their patients and manage other caregivers such as physical therapists and HHAs. This care — and the management of it all — should be covered by Medicare.

2) What methods are available to find and work with your loved one’s caregiver?  
*Use a referral.* You might be able to find quality basic care by asking people in your social and professional circles about their experience. If you trust their recommendation, this can be a great way to find a PCA or to get leads for the following two options.

*Try a registry.* Registries are listings of certified or licensed caregivers in your area. Some are compiled by locale, others by state and still others by care specialty or experience level. You can contact the individual directly and arrange an interview yourself.

*Work with an agency.* An agency handles all the legal, financial and management items, which can be a godsend for individuals who require a complicated care plan. Agencies also lay the groundwork. They’ll find the caregiver specialists your loved one needs and ensure they have the right amount of experience and the appropriate licensing.

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**Step 3. Choose the Best Caregiver**

The last step is deciding on the best fit for your loved one’s needs. Meeting with potential caregivers for an in-person interview will help you make this determination.

Essentially, picking the right caregiver for your loved one is much like making other serious decisions. You’ll need to consider everything from experience to cost to chemistry. However, keep in mind that with caregiving, chemistry is incredibly important. While you should never sacrifice training or experience for character, you do need to remember that caregiving is an intimate, long-term relationship. Your loved one needs to work well with the caregiver to get the most out of in-home care.

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According to the University of Utah Drug Information Service, as of Dec. 31, 2020, there were 129 active drug shortages in the U.S., down from 166 during the same period in 2019 and 186 in 2018. While the number of shortages is down these days, all drug shortages can have a significant impact on patient care. Notably, when “medically necessary” medicines such as immune globulin (IG) that treat rare, serious, genetic and life-threatening illnesses and have few to no alternative treatment options are in short supply, the result for patients includes chronic debilitation, permanent physical damage and even death. After experiencing two IG shortages in the U.S. since the mid-1990s, many patients and their caregivers are concerned we may be headed for another due to the COVID-19 pandemic. To better address these shortages, it helps to understand their causes and what can be done to respond to them.

IG Access: A History Lesson

Since the landmark development of the U.S. Food and Drug Administration (FDA)-approved intravenous IG (IVIG) product in 1981, the first major shortage of IG experienced in the U.S. was caused by product recalls, manufacturing-standards violations and product export. It began in 1995, when FDA issued recommendations that plasma products made from pools later found to include a donor with a fatal and little-understood disease known as Creutzfeldt-Jakob disease (CJD) be withdrawn from the market, which resulted in recalls and voluntary withdrawals. By 1997, four manufacturers that produced the vast majority of IG — Bayer, Baxter Healthcare, Alpha Therapeutic and Centeon — had recalls and withdrawals totaling approximately 7 percent of the total IVIG supply. This part of the shortage was addressed when a review of data from FDA, the National Institutes of Health and the Centers for Disease Control and Prevention suggested the risk for transmission of CJD by blood products, if it existed, was considerably lower than the risk for harm to public health from CJD-related quarantines and withdrawals, causing the Surgeon General to recommend plasma derivatives, including IVIG, be withdrawn only if the blood donor developed new-variant CJD.

Shortly after its recommendation to withdraw IVIG due to CJD, FDA doubled its inspections of plasma products manufacturers and discovered serious violations of manufacturing standards. While every manufacturer received warning letters citing numerous deficiencies, FDA allowed them to continue operating while addressing the problems. Yet, although some companies decided to continue operations, others opted to stop release and distribution of IVIG and shifted resources to compliance correction. Centeon, in particular, decided to shut down production and didn’t distribute product at all in 1997, accounting for just over half of the 20 percent shortfall. At the same time supply was diminishing, demand was surging because of newly approved indications and an increase in off-label (non FDA-approved) uses. In fact, the Immune Deficiency Foundation
and physicians across the country estimated 50 percent to 70 percent of IVIG was being prescribed off-label.

Another contributing factor to the shortage was export of IVIG. FDA reported exports accounted for up to 29 percent of distributed product, depending on the manufacturer. And, the International Plasma Products Industry Association reported exports from the major U.S. fractionators increased from 1996 to 1997, accounting for approximately 20 percent of their marketed IVIG products.³

As demand for IG products substantially increased, second shortage of IG products spanned from April 2019 through April 2020, resulting in treatment for some patients either being limited or stopped altogether. Unfortunately, while manufacturers and distributors of IG products have always contracted with one another to deliver product based on historic usage and future projections to curtail shortages, production capacity was inadequate to keep up with the increase in demand. In fact, since FDA approved the first IVIG product in 1981, IG has experienced a sustained record of near-continuous demand growth. According to Grand View Research, which forecast IVIG use until 2022, the global IVIG market size “was estimated at $9.09 billion in 2016 and is anticipated to grow at a CAGR (compound annual growth rate) of 7.1 percent over the forecast period.” North America accounts for more than 45 percent of the IVIG global market and is expected to maintain this high market share through 2022.⁶

According to Keith Berman, MPH, MBA, a blood products expert and editor of International Blood/Plasma News, “The clinical utility of IG across an ever-broadening spectrum of serious or life-threatening autoimmune, inflammatory, immunodeficiency and other immune-mediated disorders continues to be documented in patient studies and case reports now numbering in the thousands.” In addition, Berman says, there is a trend toward more aggressive treatment with high-dose IG in autoimmune neurologic diseases in particular; a steadily increasing proportion of patients being treated with long-term IG; and a growth in worldwide demand for IG products. For instance, there is a surge in IG demand in many countries in Southeast Asia, accounting for 18 percent of the market in 2014, and worldwide demand growing at an average rate of 9 percent between 2008 and 2016.⁷

In addition to many disease states now being treated with IG therapy, one of the key drivers of heightened IG demand is secondary antibody deficiencies (SAD). According to an article in Frontiers of Immunology, the prevalence of SAD is estimated to be 30 times more common than primary immunodeficiency diseases (PI), the disease for which the first IVIG product was approved and for which all IG products on the market today are indicated. Common causes of SAD include hematological malignancies such as CLL or multiple myeloma and their treatments, as well as side effects of many immunosuppressive agents and procedures involved in solid organ transplantation. According to the article’s authors, “It is becoming increasingly important to address the unmet [treatment] needs of this growing patient population,” which is progressively being treated with IG therapy.⁸

Another key driver of increased IG therapy demand is the growing geriatric population, which is prone to antibody deficiency disorders due to weakened immune systems. According to the U.S. Census Bureau, the number of people aged 65 years and older in the U.S. was approximately 46.2 million in 2014, and their numbers are expected to reach 98 million by 2060.⁹

During the period April 2019 through April 2020, IG was in short supply, resulting in treatment for some patients either being limited or stopped altogether.

To address this demand growth, Berman says, IG manufacturers must 1) forecast and invest in plasma collection facilities to ensure sufficient additional donor plasma is available to process into IG products, and 2) plan, invest and provide adequate lead time to construct and secure regulatory approval to operate new or expanded fractionation (how plasma is manufactured into IG products) and related IG production facilities.⁷

The Reasons Behind Drug Shortages

Since 1999, FDA has been working with the healthcare industry and patients to prevent and mitigate shortages of medically necessary drugs. FDA considers a drug medically necessary if it “is used to treat or prevent a serious disease or medical condition and for which no acceptable drug
Alternative is available in adequate supply."

The top reason for drug shortages involves quality concerns caused by manufacturing issues of delays/capacity (64 percent), but a lack of raw material (27 percent), boost in drug demand (5 percent) and lack of financial incentive to continue production (2 percent) can also affect drug availability. Clearly, the reasons behind previous IG shortages lend credence to these statistics.

**IG Shortage: What’s Available?**

Currently, there are 16 IG products marketed by seven manufacturers: Asceniv (IVIG 10%), Bivigam (IVIG 10%), Cutaquig (subcutaneous IG [SCIG] 16.5%), Cuvitrux (SCIG 20%), Flebogamma DIF (IVIG 5% and IVIG 10%), Gammagard Liquid (IVIG 10% and SCIG 10%), Gammagard S/D (IVIG 5%, low IgA), Gammaked (IVIG 10% and SCIG 10%), Gammagard (IVIG 10% and SCIG 10%), Gamunex-C (IVIG 10% and SCIG 10%), Hizentra (SCIG 20%), Hyqvia (SCIG 10%), Octagam (IVIG 5% and IVIG 10%), Panzyga (IVIG 10%), Privigen (IVIG 10%) and Xembify (SCIG 10%). These products — manufactured by ADMA Biologics, BioProducts Laboratory, CSL Behring, Grifols, Kedrion, Octapharma and Takeda — are deemed medically necessary drugs to treat many diseases for which it is the only therapy. IVIG and SCIG are approved by FDA to treat these diseases: chronic inflammatory demyelinating polyneuropathy, chronic lymphocytic leukemia (CLL), immune thrombocytopenic purpura, Kawasaki disease, multifocal motor neuropathy and PI. But, as mentioned previously, IG products are also prescribed to treat a host of off-label diseases and conditions, including autoimmune disorders, neurological diseases and SAD, among others.

**A Need for More Plasma**

According to Berman, “More than 90 percent of the global supply of plasma for fractionation comes from ‘source plasma,’ which is typically collected from remunerated donors in dedicated licensed centers that use automated apheresis equipment to perform plasmapheresis to separate and retain only the plasma portion of donor blood. The balance of the plasma supply comes from ‘recovered plasma’ separated from whole blood donations that is not needed for direct transfusion into hospital patients.”

Once collected, plasma (comprised of 92 percent water, 7 percent proteins and 1 percent other solutions) must go through a fractionation process that separates and collects the individual proteins, of which 64 percent are albumin, 20 percent are IgG, 2.5 percent are alpha-1 antitrypsin, less than 1 percent are clotting factors, and 13.5 percent are others such as antithrombin, protein C, Cl esterase inhibitor, etc., to produce plasma therapies such as IG, clotting factor, etc.

To try to meet the current demand for IG products, industry is growing the number of plasma collection facilities. Between 2004 and 2014, the global supply of plasma intended for fractionation doubled to nearly 40 million liters. And, in the U.S., there were 737 plasma collection centers in 2018 versus just 478 in 2014, at which more than 48 million donations of plasma were collected. Yet, despite this growth in plasma collection, Berman says, “IG product supplies here in the U.S. and internationally were — and continue to be — tight, as plasma raw material supply and IG products manufactured from it just manage to keep pace with worldwide demand growth.” In fact, he says, to keep pace with demand will require new and expanded plasma collection centers, as well as additional equipment and staff. For instance, it was calculated that an additional three million plasma donations were needed just in 2018. But now, with the COVID-19 pandemic, even more collection centers, equipment and staff may not be enough to keep up with demand. On Nov. 4, 2020, PPTA, which represents more than 860 human plasma collection centers in the U.S. and Europe, issued a statement warning of an urgent need for plasma donation. “Reports vary, but plasma collectors experienced significant declines in collections due, in part, to the impacts of social distancing measures and other mobility restrictions caused by the COVID-19 pandemic,” the statement reads. “Considering the complex manufacturing of plasma-derived therapies can take seven to 12 months, any decline in plasma donations could impact patients’ ability to access their lifesaving therapies. This sharp decline in plasma collections currently being experienced could cause more significant challenges in the months to come.”

**Optimizing IG Production**

Even if plasma collection returns to normal and continues to increase, there is a need for increased production of IG products, which is a very complicated, costly and lengthy process. After plasma is released to manufacturers, it must go through a fractionation process in which plasma that is pooled from multiple donors is processed to extract specific therapeutic proteins, which are then subjected to various purification methods and viral inactivation and removal.
processes to ensure their safety and efficacy. As PPTA mentioned, the steps and regulations required to collect donated plasma and complete the manufacturing process that results in the final therapies take between seven and 12 months. This, says PPTA, is what “sets the production of plasma protein therapies apart from chemical pharmaceuticals and other biologics whose manufacturing processes are much more condensed and whose direct manufacturing costs are a significantly smaller portion of the overall cost.”

But, despite the increase in additional plasma collection centers, IG manufacturers have been thrown another curveball: the COVID-19 pandemic.

It should be noted that IG manufacturers are stepping up to the plate. They have been investing substantially in research and technologies to increase the quality of proteins extracted from plasma, known as the “yield,” to create new and more effective therapies. The original Cohn fractionation process developed in the 1940s resulted in a significant loss in IgG-containing donor plasma. But, since the 1990s, manufacturers’ modifications to their purification processes improved the yield of IgG per liter of plasma. According to Patrick Robert, PhD, of the Marketing Research Bureau, “Over the last 25 years, plasma processing advances have improved IgG yield by roughly 60 percent on average, from 2.5 grams per liter to 4 grams or more per liter today.” Efforts continue on behalf of manufacturers to invest in new production capacity to keep ahead of forecasted future IG demand growth. And, as stated previously, the number of IG products on the market has almost doubled up to the plate. They have been investing substantially in research and technologies to increase the quality of proteins extracted from plasma, known as the “yield,” to create new and more effective therapies. The original Cohn fractionation process developed in the 1940s resulted in a significant loss in IgG-containing donor plasma. But, since the 1990s, manufacturers’ modifications to their purification processes improved the yield of IgG per liter of plasma. According to Patrick Robert, PhD, of the Marketing Research Bureau, “Over the last 25 years, plasma processing advances have improved IgG yield by roughly 60 percent on average, from 2.5 grams per liter to 4 grams or more per liter today.” Efforts continue on behalf of manufacturers to invest in new production capacity to keep ahead of forecasted future IG demand growth. And, as stated previously, the number of IG products on the market has almost doubled today compared to just 10 years ago as a result.

Meeting Patient Needs

The growing number of illnesses IG treats (PPTA reports a 66 percent increase in distribution of IG therapy between 2012 and 2018 across North America and Europe), less-than-optimal plasma supply and the complicated manufacturing process will continue to contribute to a possible IG shortage. Therefore, the healthcare industry will need to continue to take steps to optimize limited supplies for patients, including lowering doses, delaying treatments, prioritizing based on medical need and using alternative therapies when those exist.

On another front, several organizations are making efforts to improve the current situation. PPTA continues to work with some manufacturers to assist healthcare providers obtain specific products needed by patients. FDA is helping manufacturers mitigate the supply situation. It is exploring ways to improve the manufacturing yield of IG products, as well as encouraging healthcare providers, hospitals and medical systems to prospectively devise an evidence-based approach to deciding which patients will receive priority treatment. And, on the supply side, organizations such as PPTA, the Immune Deficiency Foundation and the Immunoglobulin National Society are leading the cause to encourage plasma donations during this pandemic.

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

References

Let’s Talk!

Profile: Cameron and Max Mona

By Trudie Mitschang

Trudie: Tell us about your CVID diagnosis.

Cameron: After I received my diagnosis, my immunologist suggested intravenous immune globulin (IVIG) therapy. His hope was that the treatment would prevent infections and increase my energy levels. I received my IVIG infusions over two long 10-hour days every four weeks. I had to receive my medication slowly and receive extra fluids, so the treatments took a little longer than my doctor anticipated. This treatment plan prevented the infections as my doctor intended, but the energy levels were not improving as he expected.

Trudie: What is your treatment plan today?

Cameron: After my energy levels were not improving, my nurse suggested I increase the frequency of my infusions. Once I did, I felt much better. Now, I receive my IVIG infusions once every two weeks. They only last about eight hours now, so I am not out of commission for the whole day.

Trudie: How did your life improve after IVIG?

Cameron: My diagnosis and treatment have allowed me to come as close as I can to waking up and feeling “normal.” After a long hiatus from playing baseball, I’ve been able to play varsity at my high school for the past two years, and I have been able to follow my true passion: music. IDF gave me the opportunity to learn more about CVID at different conferences I’ve attended. It’s also helped my family and friends begin to really understand what I go through on a daily basis.

Trudie: What inspired you to host a fundraiser for IDF?

Cameron: IDF has helped me and my family, and I would like to give back to the organization. Our hope is that the money the fundraiser generates will allow others in my situation to learn more about their own primary immunodeficiency diseases and help them empathize with those who suffer from CVID like me.

Max: When I had planned to climb Mount Kilimanjaro, I wanted to raise money for a cause I believed in. Within five minutes of discussing the idea, Cameron and I decided to donate all the funds we raised to IDF. The organization does amazing work and has definitely helped our family move forward with Cameron’s CVID diagnosis.

Trudie: Why Mount Kilimanjaro?

Max: I have long enjoyed mountain climbing and hiking, and I have always been very motivated by competition. Once the idea of Mount Kilimanjaro was brought up by a friend, I knew I wanted to reach the summit, and I started making travel plans soon after.

Trudie: What was your fundraising goal, and how did you promote it?

Max: Our fundraising goal was $2,500 originally, and Cameron and I quickly reached that goal. In July 2019, after rigorous preparation and training, Max successfully reached both his fundraising goal and the summit, successfully paying tribute to the little brother he considers his “hero.”

LIKE MANY families living with an immune deficiency disease, the Mona family found abundant support through the Immune Deficiency Foundation (IDF). That’s why when siblings Cameron and Max decided they wanted to raise money for their favorite nonprofit and also boost awareness about Cameron’s common variable immune deficiency (CVID) diagnosis, they decided to basically “go big or go home.” An avid mountain climber, Max floated the idea of trekking Mount Kilimanjaro (the highest mountain in Africa and the highest single free-standing mountain in the world), and right away the brothers knew they had found their fundraiser. In July 2019, after rigorous preparation and training, Max successfully reached both his fundraising goal and the summit, successfully paying tribute to the little brother he considers his “hero.”
summer between my sophomore and junior years. I was already in pretty good shape, but I put an emphasis on long-distance cardio. I spent a lot of time on the treadmill and stair climber at my gym with my hiking boots on.

Trudie: Tell us about the hike. Who participated, and what was it like?

Max: I went with three friends who were experienced climbers, having already been to the Mount Everest base camp twice, and it was a beautiful and life-changing experience. The Mount Kilimanjaro hike takes you through the jungle before your summit attempt, and I really enjoyed every moment. The most difficult aspect of the climb was during summit day. After hiking for eight hours, we briefly rested and then woke up at 1:00 a.m. to hike for 14 hours to reach the summit during the optimal time frame. Morale was low, but we were all able to summit Mount Kilimanjaro, and as you can imagine, it was quite emotional at the top!

Trudie: What has this experience taught you about yourselves?

Cameron: This experience was a big part of learning to love myself despite my illness. I used to loathe myself because of my CVID and the social and physical effects it had on my everyday life. Having an opportunity to educate others about what I go through every day showed me that although I was indeed different from a lot of other people, being different is not a bad thing. I now look at my CVID as my unique strength since it continuously presents me with adversity to conquer and grow.

Trudie: What is your involvement with IDF now? Do you plan other fundraisers?

Max: Yes! Mount Kilimanjaro was my first of the seven summits (highest mountains in each continent). Although COVID-19 has delayed my schedule, I am planning to climb Mount Elbrus in 2021, and I am continuing to raise money for IDF. As I continue to climb more difficult mountains, I plan to set higher fundraising goals and donate more money to IDF.

Trudie: What are your goals for the future?

Cameron: I am graduating high school this year and am pursuing a college education. In addition, my band Port Amerigo, in which I sing and play guitar, released our debut album “Head Rush” this December. I plan to continue to release music with the band and hopefully play shows whenever the COVID-19 pandemic becomes manageable in the United States.

Max: I plan to graduate from Concordia College in the spring, and I am planning to attend either MIT or Vanderbilt for my master’s degree. I’m also a musician, and my music duo Golden Age has recently signed with FrtyFve records, a music label in London. We plan to continue producing/releasing music in the near future. Long term, I’d love to work in either sustainable finance or in the music scene in some of the bigger cities throughout the United States.

Trudie: What advice do you have for other young adults living with CVID?

Cameron: I would say to explore your passions and not let your diagnosis define you. My condition has been manageable for years now, but fully embracing my CVID took time. Finding my passion for music and realizing that sometimes the social/physical effects from CVID are out of my control helped me do that.

Trudie: How do you keep a positive attitude toward life?

Cameron: I remain positive because I know how much progress has been made since my diagnosis. Before I was diagnosed with CVID, I remember missing school constantly, failing to gain a foothold in any social groups, and being doubted or ridiculed by teachers, peers and even some doctors. Now that I have had my diagnosis for eight years, I recognize the life I can lead is as close to normal as ever.

Max: As someone who hasn’t had to deal with the effects of CVID, I always say Cameron is my hero. He’s able to do so much and not let anything inhibit his ability, and I think that’s what’s always given me my positive outlook on life.
LAST SUMMER, my family and I took a calculated risk to visit loved ones. We packed up more suitcases than any family should own, much less be able to fill, and we set off on a westward adventure. I saw the sun rise over desert mountains, learned about the “cowboy killer” and watched my children gleefully slide down mountain waterways and hurl their brave bodies from cliffs into frigid waters. I sat up late into the night with my siblings and played Uno, and I received a call from my son who informed me he’d fallen from the tallest mountain in Sedona (he’s fine). And on the last day of our epic adventure, my stepdaughter and I jumped from a plane. I can’t say that’s something I’ve always dreamed of crossing off my bucket list or secretly longed to do; however, I have this commitment to fully living while I’m alive. So, when my stepdaughter said she was going, something compelled me to join her.

I’d be lying if I didn’t confess it was a wild experience. Something is unnerving about inching toward the open doors of a plane knowing you’ll soon propel yourself from it. My stomach dropped while the wind pummeled my face upon free fall. My mask went up my nose. It was both terrifying and glorious. Before I knew it, the instructor pulled the chute, and the ride was peaceful, serene and breathtaking.

When my feet touched the ground again, I was taken aback by the parallels between skydiving and life with chronic illness. With every flare, every new infection and every new diagnosis, we inch ourselves to the door of the plane. It’s terrifying. And yet, it’s oddly beautiful. I took the leap tandem, meaning I was strapped to the instructor’s chest and largely along for the ride. I didn’t have to make a decision about when to jump or pull the chute, but I did have to follow his instructions — one of which was to lean back onto him as far as possible as we took that initial leap. I’m not sure who you jump with in your challenge of chronic illness, but I hope they help take some of the pressure off and allow you to lean on them, especially during the scary parts. Maybe it’s a physician, a partner, close friend, parent or family member. Whoever it is, may they pull the chute and enjoy the view with you, no matter how scary the free fall.

After my jump, I felt a sense of pride I’d never felt before. I’d conquered something I doubted many could. When the instructor asked me if I could ever do it again, I reflected for a moment and realized I could. In fact, it would be much easier the next time. Much like skydiving, illness and disability challenge us to grow stronger and more capable each time we face the seemingly impossible. We gain new coping skills and become increasingly resilient.

I’m not suggesting you rush out to hurl yourself from a plane, but I do encourage you to take a moment to celebrate each of the obstacles you’ve already overcome. Think of each seemingly impossible feat you’ve faced in the past year alone! What unexpected beauty did you find amid the hardship? Did someone rally to support you? Did it allow you to better understand and empathize with others? Did you see a situation in a new light? Were you able to appreciate and love yourself more deeply? Did you learn to let go of control?

I probably won’t rush out to jump out of a plane again anytime soon. But the truth is, we’re all seasoned skydivers. Sometimes your stomach drops during free fall. Sometimes, you gain a stunning new view. When you jump next, may you remember to enjoy the view, celebrate the ones who take the leap with you and honor your own experience.

STACEY PHILPOT is an author, golfer and avid reader. You can find her blog at chronicallywhole.com, where she shares her journey of making the most of a life touched by common variable immunodeficiency, Lyme disease and rheumatoid arthritis.
It’s OK to Feel Guilty
By Michelle Searle

IF SOMEONE had told me that being diagnosed with a chronic illness would cause me to feel guilty, I would have thought they were crazy. Why would I feel guilty about having a chronic illness? And yet, since my diagnosis, I do feel guilty, and I wonder if others with a chronic illness feel the same.

Actually, having a chronic illness is accompanied by many emotions. Fear is my strongest emotion. As a child, I feared going to a doctor’s appointment or not getting better when I was sick. Now, I fear what my future will look like. But my second strongest emotion is guilt. Why do I feel so guilty? After all, I didn’t choose to be born with mutated genes. I don’t want to miss out on events, parties and time with my loved ones because I’m sick. And, I don’t want to miss school. Yet, at times, I can’t help but feel guilty during such times, and I hate that. I hate how guilty I feel when I call in sick at work or when I cancel plans — not only because I feel like I’m letting someone down, but because I want to be there and I don’t want to miss out.

I’m naturally a positive person. I try to always see the good in people and situations. When I’m going through a hard time, I remind myself I am not alone, and lots of people are going through far worse. Sometimes this reminder is helpful, but other times it makes me feel guilty. I know so many people who share my illness are sicker and have more problems than I do. And, while I don’t wish to be in their shoes, I can’t help feeling guilty when I’m upset about my illness, knowing it could be so much worse.

I’ve talked with a therapist about this, which has helped. While I still feel guilty occasionally, I’m better at allowing myself that feeling. The problem is when I compare myself to my healthier friends or family or to those who are sicker, because making these comparisons is not healthy. I have come to realize I have every right to feel bad about feeling sick or being sad. As long as I handle these feelings and allow them only to happen occasionally, then it’s OK. I hope others allow these feelings to be OK for them as well.

We have all heard of caregiver guilt, and although I’ve never experienced it, I know what it’s like to feel guilty when someone else has to take care of me. I know this is a silly thought because we all need help sometimes, but I still can’t shake that feeling when I need someone to bring me food during a bad migraine or when I need another teacher to cover my class because I’m not feeling well. It brings me joy to help others, so why don’t I believe it when others tell me they’re happy to help me?

Since I was diagnosed at a young age, I don’t know what my early years were like for my parents and family. It wasn’t until I got older and I volunteered to help children and teens with immune deficiencies that I started to see how difficult it must have been for my family — the fear they must have felt, the anxiety of watching me in pain and seeing me deal with my infusions. When I got a little older, I felt guilty I had put them through so much pain, fear and uncertainty, even though I knew it wasn’t my fault.

Frequently, my guilt arises from being too hard on myself. It’s true that sometimes we are our own worst enemies and critics. But as I’ve gotten older, I’ve become better at identifying my emotions and allowing them to be there. Of course, I still have a long way to go. Dealing with guilt is something I must always work on, but thinking and reflecting on it is the first step. I hope if you struggle with feeling guilty about your illness, you can talk about it. I’m not a therapist, but I have concluded it’s important to allow guilt to sit down at the table with our other emotions. Welcome it, talk to it, understand it and then move on from it.

Michele Searle is a teacher from South Florida who was diagnosed with common variable immunodeficiency at 11 years old. She is currently living in Italy where you will most likely find her eating pizza or trying to make friends with the local cats.
EVER SINCE my first child was diagnosed with a primary immunodeficiency disease (PI) in 2006, I have fought the temptation to keep him isolated from the “threats” of the outside world. Having two more children with the same condition has only magnified that struggle. This past year, with the emergence of the SARS-CoV-2 virus and subsequent lockdowns, I was given permission (and had no choice but) to live in what I thought would be an ideal scenario. When it all began in March 2020, I was actually excited to keep my boys at home and away from others. Finally, the entire world was living and behaving the way I wished they always would around my boys: sanitizing everything, avoiding others and covering their noses and mouths with masks during cold and flu season. And as for quarantine, I thought it would be a breeze. I was made to live in isolation!

Or so I thought. It didn’t take long for me to change my mind about how awesome life in isolation would be. And after a year of “living the dream,” I realized my kids and husband and I weren’t meant to be in close quarters together all the time. Our relationships certainly didn’t thrive without a little distance from one another, but we couldn’t be distant very often. Boredom combined with constant togetherness was one of the biggest parenting challenges during the pandemic and resulting lockdowns of 2020, not just for our family, but for families all over the world.

Even now, as restrictions are lifted for most of the population, those of us raising high-risk children such as those with PI may choose to isolate for longer periods of time until the population reaches greater levels of herd immunity. So, how can parents of chronically ill kids persevere through times of isolation and quarantine when they feel they’re barely staying afloat or when they feel guilty for lowering their parenting expectations (i.e., allowing their children more screen time) just so they can get something done around the house? With work, school and household chores all occurring in the same space and same time, it’s good to divide the workload among family members. And, kids love to watch things burn.

For those of us continuing to isolate out of medical necessity or to keep our vulnerable children safe, we definitely need a little encouragement to keep going. Countless testimonials have emerged online that provide firsthand accounts of what families did to survive the early days of quarantines and lockdowns. Parents of higher-risk children might gain inspiration from some of these suggestions:1

• Build a fire pit in the backyard. It allows for relaxation and quiet conversation.
• Invest in a trampoline for hours of fun.
• When you really need personal space, create a code word that every family member knows. When someone yells the code word, each person scatters to a different room to avoid a meltdown.
• Use the time to teach kids new chores such as folding laundry, sweeping, mopping and cooking some of their own meals. With work, school and household chores all occurring in the same space and same time, it’s good to divide the workload among family members.
• If indoors, play games as a family or have movie nights. When outside, go for bike rides or walks around the neighborhood or at a state park.
• Don’t underestimate the rejuvenating power of a daily nap — for both kids and grown-ups.

Focus on Yourself

Kids take their emotional cues from parents. If parents are stressed and overwhelmed, their children will take notice and may become anxious about life or the future. How can parents de-stress in quarantine, especially if they’re now working from home? For most families outside of quarantine, the parents’ work and the kids’ school doesn’t happen in
the same place at the same time. After the chaos of morning routines — getting the kids dressed, feeding them breakfast and packing lunches — many parents crave those precious moments of solitude during the drive from home to the office. For many, the morning commute was an excellent time to make the mental shift from parent to professional. But when the commute disappears, so do those moments of solitude. When a parent never leaves home, when does that time-out happen?

If possible, parents should try to carve out some time for themselves to regroup, mentally refresh and de-stress. This could include taking a daily walk during lunch breaks, purchasing a gym membership or investing in home gym equipment, and taking time to focus on physical health and wellness.

Because stress and mental fatigue can creep in after nonstop time with kids and working from home, implementing muscle relaxation techniques, slow breathing and mindfulness practices into a parent’s everyday schedule can help keep stress levels down.

Ease Children’s Anxiety

Many children who aren’t normally anxious might be struggling with the knowledge of a potentially harmful virus circulating the globe. Kids’ lives have been upended during the last 12 months with changes to their school routines and sports seasons canceled. If parents notice their children seem to be experiencing feelings of anxiety or even anger at COVID-19, there are ways to help:

- Validate their feelings by explaining no emotion they’re feeling is wrong or bad.
- Monitor the media. With constant news coverage of the pandemic, kids might feel overwhelmed with all of the dismal statistics and frightening images of people in hospitals. Parents should remember to turn off the TV at times and discuss topics other than the virus.
- Create a routine. Make a daily schedule for each family member, and include lunch breaks, recess, snack time and class times. With different family members all working, Zooming and taking breaks at different times, things can get chaotic. Keeping a schedule can lower stress levels by making sure everyone knows what everyone else is supposed to be doing and when. Also, set an established wake time and bed time for kids, and try to be consistent. Even if they’re learning from home, they don’t need to stay up later or sleep in longer than usual.

Set Boundaries

When parents who normally work outside the home have to work remotely, the home/work boundaries normally in place begin to blur. It becomes more challenging to get things done or disconnect from work. To help keep these distinctions, parents should designate a specific area to work in, preferably a room with a door to keep distractions to a minimum. Setting up a laptop on the kitchen counter makes it easier to keep an eye on the kids, but focusing on work becomes almost impossible. Make sure children understand that even though the parents are home, they are working. And children should be given positive reinforcement, even a simple thank you, for not interrupting their parents while working.

Children should also have a designated area for doing schoolwork and homework. Their bed, where they may be tempted to drift off to sleep, may not be the ideal location. The more kids are at home trying to distance learn, the harder it is to find separate spaces — especially when kids share a bedroom — but they need to find room to spread out, even if it’s at opposite ends of a larger room.

Going Forward

As this current pandemic hopefully winds down and things settle back into what will be our “new normal,” parents of high-risk children can take what we’ve learned during this unprecedented time — coping strategies, stay-busy activities, stress-reducers — to prepare for whatever comes next. We can be almost certain this won’t be the last pandemic we’ll face in our lifetimes. But we know that should another novel virus arise in the future, some parents have the ability to work remotely. Our children can learn from home. We can adapt. We can make lifestyle changes. The priority is staying healthy — both mentally and physically — and families have to decide for themselves how to best accomplish that goal. COVID may have caught some of us off guard, but with the learning curve that is gained from experience, we won’t be flying blind next time.

References

According to the National Institutes of Health, nearly 24 million individuals suffer from an autoimmune disease, many of which interfere with sleep. For example, autoimmune disorders such as lupus, multiple sclerosis, Guillain-Barré syndrome and Graves’ disease cause hormonal and nerve imbalances that disrupt sleep. In addition, immune globulin treatments for primary immunodeficiency disorders can lead to hot flashes, chills, anxiety and other issues that are not exactly the ideal recipe for rest and relaxation. Yet, while medications can help promote sleep, a growing number of Americans are opting for more natural alternatives such as aromatherapy.

The Oily Evidence

Although aromatherapy has existed for thousands of years, the essential oils-based health and wellness treatment is experiencing an upward trend and is expected to continue to grow, according to Grand View Research, a market research and consulting company. Driven by a desire to maintain a healthy lifestyle, while steering away from pharmaceutical drugs, more individuals are looking at the various benefits of aromatherapy that include everything from reducing stress and anxiety and relieving migraines to treating insomnia and digestive and respiratory ailments.

Essential oils are literally compounds extracted from herbs, flowers and other plants. After capturing the plant’s scent and flavor (or essence) through distillation or cold-pressing, the essential oil can be added to a carrier oil, sprinkled into water and diffused into the air or added to a capsule and ingested.

To take advantage of the therapeutic properties of essential oils, they can be inhaled or absorbed, and some can even be ingested. Inhalating the aromas can stimulate the limbic system, the part of the brain that plays a role in emotions, behaviors, sense of smell and long-term memories. In addition, the limbic system helps control unconscious functions such as breathing, heart rate and blood pressure. When applied to the skin, the chemicals from the plants can help penetrate through the layers of skin more easily.

Perfect for Any Situation

While the claims about aromatherapy may not be concrete, there’s no denying this: A small plume of lavender-scented stem twirling from the depths of a diffuser add an undeniable calmness and delightful smell to any situation.

Multiple studies indicate they can help treat a variety of ailments.

In a 2012 study published in the Journal of Alternative and Complementary Medicine, researchers looked at the effect of sweet orange aroma to treat anxiety. The result? The group that inhaled the allegedly calming aroma, versus tea tree oil or water, exhibited a lack of anxiety and tension. The journal has published other studies revealing aromatherapy’s positive effect on anxiety and stress.

Other studies have shown lavender harbors antiviral, antimicrobial and antibacterial properties, but its sweet floral scent can help ward off stress and induce sleep.

Many aromatherapy advocates swear by the power of an oil blend called “thieves.” Commonly composed of cinnamon, clove, eucalyptus, lemon and rosemary, thieves is purported to boost the immune system, fight off nasal and sinus congestion and promote respiratory and cardiovascular health. Also, its alleged antimicrobial properties — some studies have shown it inhibits the growth of pathogens — make it an ideal, toxic-free cleaning product.

Flower Power

While much of the evidence surrounding essential oils is anecdotal,
Just Clip It
Need to bring the power of aromatherapy along for the ride? Simply add a drop of essential oil to the mini nasal inhaler, place in your nose and you’re set. These tiny devices help relieve congestion, headaches, nausea or insomnia by providing a targeted and continuous flow of aromatherapy, no matter where you are. The inhalers are adjustable and available with two or four holes. $12.99; www.amazon.com/Essential-Inhaler-Unscented-Reusable-Refillable/dp/B088ZRWLZH?ref_=bl_dp_70

Steal Some Immunity
Fill any space with the healing properties of Young Living’s Thieves oil blend. To achieve the spicy aroma, the company combines cinnamon bark, clove, eucalyptus radiata, lemon and rosemary oils. In addition to the essential oil, Young Living’s proprietary oily blend is also available in home cleaning and personal care products, including household cleaner, detergent, hand purifier, wipes and hand soap. Prices vary; www.youngliving.com/en_US/products/c/thieves

Scent-Worthy Subscriptions
Always heading to the store to stock up on more lavender oil? Once aromatherapy becomes a part of the day-to-day routine, some individuals find themselves running out of their favorite essential oils fast. Monthly memberships to companies such as doTERRA and Young Living often come with perks and help ensure you get your oily fix without stepping out the front door. Prices vary; www.doterra.com/US/en/membership-comparison; www.youngliving.com/en_US/opportunity

Designer Diffusers
Not exactly overjoyed to introduce a not-so-cute diffuser into your home? No problem. These days, many diffusers are designed as pieces to showcase, instead of hide, the beneficial aromas of essential oils. In white or black matte metal or the company’s signature stone in a variety of shades, Vitruvi’s diffusers are a pretty addition to a home’s esthetic. $119 to $179; vitruvi.com/collections/diffusers

Stylish Scents
Want to look cute and smell great, all while enjoying the therapeutic benefits of essential oils? Simply clip on a Matrix Aromatherapy diffuser necklace or bracelet. The necklaces are available in two sizes in either stainless steel or rose gold, while the bracelets are crafted with naturally porous lava stones and available in a variety of colors. The necklaces are packaged with three aromatherapy pads, and refills are available on the site. $14.99 for the bracelets and necklaces start at $17.99; www.matrixaromatherapy.com

Just Breathe
Block out the light and breathe in the calming scent of lavender and chamomile flowers with a linen aromatherapy eye pillow. Made with soft linen and available in an array of soothing colors, Bodha’s therapeutic eye pillow helps release facial tension by engaging acupressure points that soften the delicate muscles surrounding the eyes. $38; standarddose.com/collections/bodha/products/bodha-linen-aromatherapy-eye-pillow

Shopping Guide to Aromatherapy Products
**Book Corner**

**When Your Child Has a Chronic Medical Illness: A Guide for the Parenting Journey**
*Authors: Frank J. Sileo, PhD, and Carol S. Potter, MFT  
Publisher: APA LifeTools*

Written by leading mental health professionals, this book about children with chronic illnesses offers clear, practical guidance for all aspects of the journey. It places psychological well-being front and center, so parents can be the best caregivers possible for their child. Along with suggestions for making laughter and mindfulness part of the daily self-care routine, it offers guidance for choosing the right therapist for the family should extra support be needed. Every family’s journey with chronic illness is unique, but parents don’t have to go it alone.

**How to Be Sick: Your Pocket Companion**
*Author: Tony Bernhard  
Publisher: Wisdom Publications*

The is a pocket-sized guide to the practices of the best-selling classic that helps readers cope with the pain and uncertainty of illness and navigate their relationships with family, friends and medical professionals. The author shares practices from her bestselling classic *How to Be Sick* and also offers new suggestions and strategies for coping with a life impacted by chronic pain and illness. Because the book is organized by specific challenges, readers can immediately find practices that can help when they’re needed most.

**New and Useful Reading**

**Happiness Is an Option: Thriving (Instead of Surviving) in the Era of the Internet**
*Author: Lynda M. Ulrich, DMD  
Publisher: Transcendent Publishing*

Through life experiences, Dr. Ulrich has learned how people can see themselves not as victims of the Internet’s chaos but as the solution if one fundamental secret of the web is understood. She inspires readers with stories of goodness and progress underway in a world that few people know about. It’s a discovery she calls the “Conspiracy of Goodness.” With four simple shifts — learned after decades of working alongside thought leaders and innovators who are changing the world — individuals can start seeing the other side of the story, the one left untold on social media and the 24-hour news cycle. The tools in this book are intended to help readers move from a world of division to one of discovery, and show them how they can use their differences in remarkable ways to change the future.

**Primary Immune Deficiencies Made Simple**
*Author: Sagar Bhattad, MD  
Publisher: CBS Publishers and Distributors Pvt Ltd.*

Primary Immune Deficiencies Made Simple is a compilation of real-life cases that bring the science of immunology and primary immune deficiencies from bench to bedside. Written by a pediatric immunologist, the book aims to simplify the subject for pediatric trainees, internists and physicians. It features case-based learning, clinical algorithms, age norms for immunoglobulins and lymphocyte subsets, and a description of common immune deficiencies in an easy-to-understand format.
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Ataxia Telangiectasia (A-T)
Websites
- A-T Children’s Project: www.atcp.org

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
Websites
- GBS/CIDP Foundation International: www.gbs-cidp.org

Evans Syndrome
Online Peer Support
- Evans Syndrome Research and Support Group: www.evanssyndrome.org

Guillain-Barré Syndrome (GBS)
Websites
- GBS/CIDP Foundation International: www.gbs-cidp.org
- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Idiopathic Thrombocytopenic Purpura (ITP)
Websites
- ITP Support Association – UK: www.itpsupport.org.uk
- Platelet Disorder Support Association: www.pdsa.org

Kawasaki Disease
Websites
- American Heart Association: www.heart.org/HEARTORG/Conditions/More/CardiovascularConditionsofChildhood/Kawasaki-Disease_UCM_308777_Article.jsp?T12b0spW5O
- Kawasaki Disease Foundation: www.kdfoundation.org
- KidsHealth: kidshealth.org/parent/medical/heart/kawasaki.html

Mitochondrial Disease
Websites
- United Mitochondrial Disease Foundation: www.umdf.org
- MitoAction: www.mitoaction.org

Multifocal Motor Neuropathy (MMN)
Websites
- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Multiple Sclerosis (MS)
Websites
- All About Multiple Sclerosis: www.mult-sclerosis.org/index.html
- Multiple Sclerosis Association of America: mymsaa.org
- Multiple Sclerosis Foundation: www.msfocus.org
- National Multiple Sclerosis Society: www.nationalmssociety.org

Online Peer Support
- Friends with MS: www.FriendsWithMS.com
- MSWorld’s Chat and Message Board: www.msworld.org
- Overcoming Multiple Sclerosis: overcomingms.com/community

Myasthenia Gravis (MG)
Websites and Chat Rooms
- Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org

Online Peer Support
- Genetic Alliance: www.geneticalliance.org

Myositis
Websites
- The Myositis Association: www.myositis.org
- International Myositis Assessment and Clinical Studies Group: www.niehs.nih.gov/research/resources/imacs

Online Peer Support
- Juvenile Myositis Family Support Network: www.curejm.org
- Myositis Association Community Forum: tmacommunityforum.ning.com
- Myositis Support Group – UK: www.myositis.org.uk

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococci (PANDAS)
Websites
- PANDAS/PANS Advocacy and Support: www.pas.care
- PANDAS Network: www.pandasnetwork.org
- Midwest PANS/PANDAS Support Group: www.midwestpandas.com

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

Peripheral Neuropathy (PN)
Websites
- Neuropathy Action Foundation: www.neuropathyaction.org

- Western Neuropathy Association: www.pnhelp.org
- Neuropathy Alliance of Texas: neuropathylliancecto.org
- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Primary Immune Deficiency Disease (PI)
Websites
- Immune Deficiency Foundation: www.primaryimmune.org
- Jeffrey Modell Foundation: www.info4pi.org
- The National Institute of Child Health and Human Development (NICHD): www.nichd.nih.gov/Pages/index.aspx
- American Academy of Allergy, Asthma & Immunology: www.aaaaai.org
- International Patient Organisation for Primary Immunodeficiencies (IPOPI) — UK: www.ipopi.org
- New England Primary Immunodeficiency Network: www.nepin.org
- Rainbow Allergy-Immunology: www.uhospitals.org/rainbow/services/allergy-immunology

Online Peer Support
- IDF: www.idffriends.com
- Jeffrey Modell Foundation Facebook Page: www.facebook.com/JMFworld
- IDF Peer Support Program: www.primaryimmune.org/idf-peer-support-program

Scleroderma
Websites
- Scleroderma Foundation: www.scleroderma.org
- Scleroderma Research Foundation: www.sr4cure.org
- Johns Hopkins Scleroderma Center: www.hopkinsscleroderma.org

Online Peer Support
- Scleroderma Support Forum: curezone.com/forums/fasp?Id=404
- International Scleroderma Network: www.sclero.org/support/forums/a-to-z.html

Stiff Person Syndrome (SPS)
Websites
- American Autoimmune Related Diseases Association Inc.: www.aarda.org
- Genetic Alliance: www.geneticalliance.org
- Living with Stiff Person Syndrome (personal account): www.livingwithspss.com
- Stiff Person Syndrome: www.stiffpersonsyrondrome.net
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