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Staying Safe During the Pandemic

As the COVID-19 pandemic surges on and infection rates and hospitalizations continue to rise in the U.S. and abroad, patients with primary immunodeficiency (PI) diseases and other illnesses that place them at higher risk of infection and severe complications must take steps to mitigate exposure to the SARS-CoV-2 virus.

While many people have opted to forgo elective healthcare treatments to limit their exposure to the virus, postponing care is not possible for PI patients who require immune globulin (IG) treatment to stay alive. But, as blood products expert Keith Berman, MPH, MBA, explains in his article “No Place Like Home: The Growing Acceptance of Subcutaneous Immune Globulin” (SCIG) (p.16), now might be a good time for these patients to consider switching to SCIG to safely receive IG treatment at home. Indeed, SCIG therapy offers many advantages in addition to the greater safety of remaining at home, including convenience, fewer side effects and more stable IgG trough levels to eliminate the malaise often felt by patients in the weeks leading up to their next intravenous IG infusion. Understandably, SCIG is not a practical choice for all, but Berman provides ample evidence for why PI and autoimmune neurological patients who qualify for SCIG due to increased risk factors of COVID-19 exposure opt for this route of infusion.

The growing use of telehealth due to the pandemic adds yet another safety measure for patients. The scope of services now provided via telehealth is remarkable, including dermatology and eye exams. Our article “Taking Advantage of Telehealth Services” (p.28) discusses how to determine what types of visits would be appropriate given the situation and whether they would be covered by insurance, as well as how to prepare for a visit by choosing a platform and location and even what to wear.

Regrettably, even while the options for staying safe during the pandemic are increasing, the damaging consequences of prolonged social isolation are taking both a mental and physical toll on many. As we explore in our article “Effects of Social Isolation on Overall Health” (p.34), this is especially true for individuals with chronic illnesses who may already be struggling with depression and anxiety. Thankfully, as we note, there are positive steps people can take to protect their mental health during these times, and if needed, there is help available.

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
Avoid Being Penny Wise and Pound Foolish When Purchasing Health Insurance

By Abbie Cornett

I HAVE always been a person who tries to purchase items on sale. As my husband jokes, I have never met a discount rack I didn’t love. Sometimes, though, this hasn’t worked particularly well, especially when I was younger and didn’t understand the meaning of value! I would buy cheap things that just happened to be on sale rather than good products, which frequently meant what I bought didn’t last very long or I didn’t like it and wouldn’t use it. When this happened, my mother would look at me and say, “Abbie, don’t be penny wise and pound foolish.” It took several disappointments for me to understand the wisdom of this old British saying: When trying to save a small amount of money, be sure it isn’t going to cost more in the long run.

I can think of no better example of the importance of being penny wise and pound foolish than when individuals with a chronic illness are choosing a health insurance plan. For most people, selecting a plan is a relatively simple process. They pick a plan, they may or may not get a physical and it covers most of their expenses for the year. But for people with a chronic illness, this isn’t how it works! An insurance plan can make or break finances and access to treatment.

I understand how difficult finances can be for people with a chronic illness. In addition to everyday expenses, you have the cost of frequent doctor visits, medicines and medical supplies. Further, having a chronic illness can affect your ability to work and earn income. And, these are only a few reasons the right insurance plan is so important. Unfortunately, many patients try to save money by picking a less-expensive plan only to find out later that the plan doesn’t cover their medical needs, or their out-of-pocket expenses are more than they can afford.

Enrolling in health insurance can be confusing even for people with uncomplicated health needs. So, before making any purchase, research the policy you are considering to ensure it will cover your situation. Some examples to consider:

• Does the policy allow you to see your doctors, or do you have to change to in-network doctors?
• If your physician isn’t in-network, how much will it cost you to continue seeing him or her?
• Does the policy cover your specific medications?
• If you need medical equipment, how often will the insurer cover replacements?
• What will your out-of-pocket expenses be? While a high-deductible plan may make sense for many people, it doesn’t for those who have greater medical needs. The out-of-pocket expenses for a person with a chronic illness can frequently be more than the additional cost of a low-deductible plan.

How do you obtain the answers to these questions? When researching insurance plans, it is important to know the Affordable Care Act requires insurance companies and job-based health plans to provide you with a short, plain-language summary of benefits and coverage (SBC) and a uniform glossary of terms used in health coverage and medical care. This information helps you make “apples-to-apples” comparisons when looking at plans.1

And, while the SBC can help you understand what a policy covers, you often need to conduct more research to determine whether the plan covers specific providers, hospitals and medications. This can be accomplished by accessing the insurance company’s online portal or contacting the company directly. If you contact the company by phone to get a determination of coverage, I suggest you document the date, time and the representative you spoke with or, better yet, request that person send you an email detailing what was stated regarding coverage.

When you’re diagnosed with a chronic illness, understanding insurance coverage becomes vital to your financial success. Not only do you need to be confident you are selecting the best healthcare plan to limit out-of-pocket expenses and maximize treatments, you also must ensure the plan meets your individual needs. Saving money on your premium might seem like you will pay less, but it could cost you a lot more money in the long term or, worse, limit access to your needed medication. 

Reference

ABBIE CORNETT is the patient advocate for IG Living magazine. She can be reached at patientadvocate@igliving.com or (800) 843-7477 x1366.
Have You Had to Get Reauthorization for Treatment?

Every single year. It’s infuriating that when we have a rare disease for which we rely on medicines to stay alive that we have to continually “prove” need! Shame on the insurance industry! — Renee WL

Every six months for immune globulin (IG), plus every month the specialty pharmacy has to check with my insurance again before they will ship the drug, even though it is already authorized. My insurance company denied IG until my immunologist appealed and did a peer to peer, [since] they wanted me to try and fail three other drugs first. Now they are doing it again with an arthritis drug, saying I need to try and fail six other drugs before they will approve the drug my rheumatologist wants me to take. — Alicia S

Yep, and then insurance ends up with the $100,000-plus hospital bill instead of letting me receive home intravenous immune globulin for $10,000. Makes total sense! — Becca L

No, and I consider myself incredibly lucky that I don’t. The stories I have heard from other people who do have to get their infusions authorized are so scary. These insurance companies don’t seem to understand that we need our infusions to live and/or have a decent quality of life! — Mary-Jane M

Do You Feel Like You Have to Apologize for Being Sick?

Yes, I do! My disease is so unpredictable that no matter what plans I make, it seems a lot of the time I am unable to do what I have committed to. It’s really hard sometimes. — Jenny G

I feel like my work has never thought of me as someone who should be considered for any higher position because I get sick. — Jane N

Is It Celiac or Common Variable Immune Deficiency (CVID)?

I’ve been tested multiple times over the decades. You have to be eating gluten for a number of months in order for them to test. So, if you’ve been off of gluten for a while, then the test for celiac is going to be negative even though you might have it. The only way to know for sure is to have a biopsy, and they can do that when they’re doing a colonoscopy. — Rachel D

From my understanding, if you have low IgA, the blood test they typically use to determine celiac might not be accurate and could reflect a false-negative. I believe you have to do more involved testing (genetics). — Laura C

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.
How long does it take for IVIG to work when treating dermatomyositis?

I have been diagnosed with dermatomyositis, lupus, mixed blood disorders, rheumatoid arthritis and Friedreich ataxia, and I am currently having a major flair of dermatomyositis. I just received my third intravenous immune globulin (IVIG) infusion, and I am wondering when I will see improvement.

Abbie: I spoke with Terry O. Harville, MD, PhD, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, regarding your question, and he said there are several approaches to treating dermatomyositis depending on laboratory values, prior treatments and comorbid conditions. IVIG at 2 g/kg has been found to be quite useful for treating dermatomyositis, but it is not typically the only medication prescribed. Patients may also receive corticosteroids to help reduce disease severity. Further, methotrexate may be used to help reduce the need for corticosteroids, and then IVIG can be added to help fully stop the flair. Some patients receive Rituximab, which has been shown to be very helpful. According to Dr. Harville, how long treatments take to work “depends on many factors, including age, longevity and course of disease, other treatments prescribed, comorbid conditions and the dose of IVIG.”

Can dermatomyositis be treated with SCIG?

I have been diagnosed with dermatomyositis, and I am treated with 65 grams of intravenous immune globulin (IG) for two consecutive days every two weeks. Can dermatomyositis be treated with subcutaneous IG (SCIG) instead?

Abbie: I spoke with Michelle Greer, RN, IgCN, senior vice president of sales, and Joseph DiStefano, RPh, IgCP, CSP, director of clinical programs at Nufactor, a Specialty Pharmacy Company, regarding your question, and they said SCIG can treat dermatomyositis; however, it would involve a lot of subcutaneous sites and infusions multiple times per week. For example, to convert from IVIG to SCIG, approximately 65 grams would have to be administered subcutaneously weekly using a 10% SCIG product. However, a 20% solution would require less volume compared to a 10% solution since 65 grams of a 10% solution equals 325 mL of a 20% solution. If a 20% solution (CSL Behring’s Hizentra) were administered, it would be reasonable to round down to 60 grams of 300 mL each week for ease of administration and vial size availability. Following Hizentra CIDP guidelines, the dose should be titrated as tolerated. Greer and DiStefano’s recommendation would be to start with 20 grams per 100 mL solution into five subcutaneous sites three times per week. However, it really depends on how the patient absorbs and tolerates the volume per subcutaneous site. The dose and volume per site could be given in many combinations and as infrequently as 300 mL into six sites once per week, which a patient who weighs more than 250 pounds should be able to accommodate.

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

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MOST OF US procrastinate at times. However, ongoing procrastination has been shown to contribute to problems with work or school performance, increased feelings of shame and guilt, increased symptoms of depression or anxiety, and worsening physical health.

Procrastination is different from real problems with attention; it is avoiding tasks. Fifteen percent of people in the U.S. avoid tasks, with older people procrastinating more than younger people. And people who struggle with depression or anxiety are more likely to procrastinate compared to people who do not struggle with these problems.

Procrastination is not being disorganized or lazy. For most, it is about emotion regulation or the desire to avoid uncomfortable feelings such as anxiety, sadness or frustration and uncomfortable thoughts such as “I can’t do this” or “If I don’t do this perfectly, I’m a failure.” We all have that unhelpful voice in our heads that says things like this sometimes. However, some of us try to avoid these thoughts and feelings by procrastinating. So, if you are someone who procrastinates, following are behavioral and mindfulness exercises that may help.

Behavioral exercises:
1) Divide the task into bite-size chunks. Then focus on completing each manageable piece rather than the entire project.
2) Alternatively, schedule short periods of time to work on the task regardless of how much you complete. Schedule 15 minutes to work on the task, and only work on it for that 15 minutes.

While doing either of these two exercises, all of those uncomfortable thoughts and feelings about the project will probably arise. However, it is easier to tolerate them if you know it has to be done only for a short period of time as opposed to “until the task is done.” Some people find once the small task or 15 minutes is up, the anxiety or frustration are less intense than when they started. Others find they want to continue working on the task after the exercise is over. If either of those things happen, that’s great. If not, remember the goal is to simply set aside a small block of time each day to work on the project. Each time you do this exercise, it will become easier.
3) Remove distractions while working on the task. Close your email. Turn off your phone. Turn off notifications. They will all still be there when you are done. Email, texts and social media love to help people procrastinate.
4) Reward yourself for each small victory. After completing each small task or 15-minute session, do something you enjoy or buy yourself something small. Believe it or not, this strategy is really powerful, even when we’re rewarding ourselves.

Mindfulness exercises:
1) Try to take notice of the urge to put the task off. Don’t judge the urge, just notice it. Where do you feel that urge in your body? What does the sensation feel like? Breathe through the sensation.
2) Think about your motivation for completing the project. Why does completing it matter to you? What values are relevant? Maybe you need to finish a task for school or work. Is that because you value being responsible? Or, is it because you want to be successful? Think about the values behind the goal. Write them down and leave them out where you can see them while working on the task.
3) Mindfulness exercises also improve your ability to sustain attention on a task, which will help you complete it. Take a minute to just focus on your breathing, to feel your body in the chair beneath you or to close your eyes and notice what sounds you hear.
4) Use one of the great apps such as Calm, Headspace and others that have short (5-minute to 15-minute) mindful meditation exercises.

Procrastination is a real problem. It does not mean you are lazy or disorganized. But, it does mean you need to try some strategies to tolerate the uncomfortable thoughts, feelings and urges that come up so you can get the project done.
WE HAVE discussed true allergic disease caused by IgE antibodies, which is known as type I hypersensitivity in the Gell and Coombs classification system of histopathologic reactions (type I, type II, type III and type IV hypersensitivities). In contrast to type I hypersensitivity, which is mediated via IgE, type II hypersensitivity is mediated via IgG and IgM antibodies, and complement activation is typically required to produce damage. Complement is activated by the IgG subclasses IgG1, IgG2 and IgG3, but not by IgG4. Consequently, IgG4 is not typically considered to cause type II hypersensitivity. Type II hypersensitivity is sometimes referred to as “direct-antibody cytopathology” or “cell cytotoxicity” due to the damaging effects caused by the antibodies and complement, which can result in cell death.

Under normal circumstances, type II hypersensitivity acts as first-line immune protection to kill invading microorganisms. For example, if someone develops antibodies against streptococcus, and streptococcus tries to invade the body, these antibodies are readily available to bind to the surfaces of the invading bacteria. When two of the bound antibodies are close enough, complement C1q binds and crosslinks the antibodies. This initiates the complement cascade that forms the complement membrane attack complex, which in turn creates a hole in the bacterial membrane, allowing water to rush in and essentially cause the bacteria to explode. This process is a critical component of a person’s immune system to provide early surveillance or first-line protection against invading microorganisms since it is always on guard and does not require specific immune cell activation at the time the microorganisms invade.

For type II hypersensitivity involved in pathologic disease, an IgG or IgM antibody is present that can bind to a cell surface protein or other cell surface component such as a polysaccharide chain. This is referred to as an autoimmune antibody when it is directed to a component on one’s own cells (self). If the antibody is directed to another person’s cell surface components (nonself), it would be referred to as alloimmune. As shown in the figure, an antibody can bind to a cell surface protein. When two surface-bound antibodies are close to

Figure. Type II Hypersensitivity Demonstrated by an IgG Antibody Binding to a Cell-Surface Protein, with Subsequent C1q Binding and Crosslinking, with Subsequent Complement Activation and Formation of the Membrane Attack Complex

A. Depiction of the components involved with the type II hypersensitivity: 1) IgG antibody (this could be autoimmune to self, or alloimmune against nonself, or it could be an IgM autoantibody or alloantibody, instead of IgG), 2) complement C1q, 3) cell surface protein (this could also be a polysaccharide polymer) and 4) membrane attack complex (MAC). For brevity, complement proteins C2, C3 and C4 are not shown in the diagram.

B. Autoimmune antibodies binding to cell surface proteins with subsequent complement C1q binding and crosslinking. For brevity, complement proteins C2, C3 and C4 are not shown in the diagram.

C. Complement cascade activation and subsequent formation of the MAC. When C1q binds and crosslinks antibodies, it becomes activated to bind and activate the complement proteins C4 and C2 (not shown in the diagram). The complex of C4/C2 then activates complement protein C3 (not shown in the diagram). The activated C3 complex acts on complement protein C5, which then initiates the ultimate formation of the MAC (made from complement proteins C5, C6, C7, C8 and C9), forming a pore through the cell membrane, essentially a hole, which allows water to enter into the cell that can disrupt the cell and cause cell death.
each other, complement C1q binds and crosslinks the antibodies. This activates the complement cascade and results in specific complement proteins creating a pore in the cell membrane, which can subsequently result in cell death.

Perhaps the most common form of type II hypersensitivity occurs with blood transfusions. For example, if someone has blood type A, he or she will likely have made anti-B blood type antibodies (anti-A and anti-B antibodies are known as isohemagglutinins and are typically IgM antibodies). So, if this person were transfused with a B blood type, their anti-B isohemagglutinins would bind to the red blood cells (RBCs), activate complement, poke holes in the RBCs and destroy them (hemolysis). Another example occurs with organ transplantation rejection. In this situation, anti-HLA antibodies made by the patient and directed against the donor bind to donor HLA proteins expressed on the donor cells of the organ, resulting in complement-mediated damage to the donor cells, which can result in graft failure. Transfusion reactions due to blood type incompatibility and antibody-mediated graft rejection are considered a result of alloimmune antibodies, those directed to nonself cell surface components.

Autoimmune hemolytic anemia and autoimmune thrombocytopenia are a result of type II hypersensitivity caused by antibodies directed to self cell surface components.

In the next issue, we will continue with the discussion of type II hypersensitivity.

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**Preparation to Begin IG Therapy**

By Surayyah Morris, PharmD

**IMMUNE GLOBULIN (IG)** is a sterile solution made from healthy donated human plasma containing antibodies that protect against infection from various diseases. For primary immunodeficiency (PI) patients, IG is prescribed to supplement their bodies’ antibodies that are lacking in inadequate numbers and/or quality. For autoimmune disorder patients, IG helps to keep their immune systems from attacking their bodies’ healthy antibodies. PI patients who require replacement antibodies are generally prescribed lower doses of IG, whereas autoimmune disorder patients are generally prescribed higher doses. And, while most PI patients receive IG therapy for life, not all patients require IG therapy indefinitely.

When starting IG therapy, a variety of issues must be considered, including route of administration, site of infusion and side effects. Following are tips to make beginning IG therapy easier depending on each person’s situation.

**Prescriptions**

Before IG infusions begin, a doctor has to write a prescription for the medication. That prescription may be for intravenous IG (IVIG) infusions in a clinic or hospital or at home with a nurse. Or, it may be for subcutaneous IG (SCIG) infusions at home. The doctor will note on the prescription the IG medication (there are currently 16 different products), dose, infusion rate and the number of infusions over the course of a year. In addition, prescriptions should be written for any necessary pre/post-infusion fluids, steroids, pain, anti-inflammatory, anti-nausea and/or antihistamine medications.

**IVIG Versus SCIG**

IVIG and SCIG differ in their route of administration and concentration of the drug. IVIG is infused directly into the body through a vein and is immediately absorbed. SCIG is infused through one or more subcutaneous needles inserted under the skin into subcutaneous fat. While the absorption is not as quick as with IVIG, it is still fast and effective. SCIG medications are also more concentrated than IVIG products; therefore, these infusions use less volume of medication and take less time to infuse. SCIG can also be infused without the assistance of a nurse or doctor.

**Site of Infusion**

It is important to know well in advance where the infusion will take place. If the infusion will occur in a hospital, a trial walk-through can help determine where to go and who to speak to on infusion day. If the infusion will occur in an outpatient infusion clinic (such as a cancer center), patients should ask the clinic about its processes and procedures for administering the drug. It should also be determined whether the clinic will provide supportive care and what comfort items patients are recommended to bring.

If the infusion will occur at home with help from a nurse, patients should confirm the nurse will bring the medication and necessary supplies. For subcutaneous infusions performed at home, the medication should be received prior to the infusion from the specialty pharmacy, and it should be checked to verify that all medications and supplies are correct and in the right quantities. Pharmacies sometimes make mistakes, so patients need to ensure they have adequate supplies for the quantity of medication that will be infused.

**Supportive Care**

For all sites of infusion, it will help to have the following items:

1) Water (It is important to hydrate daily, but it is especially important on the day or two preceding the infusion,
as well as several days after the infusion since hydration helps to prevent severe headaches, one of the worst side effects of IG therapy.

2) Premedications such as steroids, antihistamines and/or Benadryl

3) Anti-nausea remedies (ginger tea, Zofran, alcohol swabs)

4) Blanket, comfy socks, hoodie sweatshirt

5) Hobbies such as crafts, puzzles, books, movies, i'Pad or a friend if allowed (Infusions can take a while.)

6) EpiPen (epinephrine injection) (Patients should make sure they know how to use one and to always have one available when not in an inpatient setting.)

**Side Effects**

There are possible side effects with IG therapy, as well as management strategies should they occur. Headache, flu-like symptoms, fatigue and skin site reactions are the most common side effects patients experience. And, while some side effects may occur during the infusion, others may present hours or even days later. Many IVIG reactions can be addressed by drinking more fluids prior to infusions, slowing infusion rates and administering premedications. Side effects associated with SCIG can be managed by proper needle insertion technique and changing needle length, rate of infusion and other factors. The supportive care tips are the best way to mitigate the common side effects of IG therapy.

**Keeping Track of Infusions**

Patients should keep track of the dates, times, duration and rate of infusions, the brand, strength and lot number of each vial of IG and other medications or care provided. It can help to document where the IV or SC needles are placed. In addition, it should be noted how patients are feeling before, during and after infusions and whether any side effects were experienced, their intensity and how long they lasted.

**What Else to Know**

1) Patients are prescribed IG therapy for a variety of reasons, and each patient will be affected differently by it. While it is helpful to get the insight and experience of others through support groups or online communities, patients need to determine what works best for them, including the brand, dose, time it takes to experience any benefit, side effects, as well as infusion method and site.

2) Lab tests that evaluate certain diseases or conditions using serology (immune blood tests) testing may produce a false-positive result. For example, if a patient prescribed IVIG is tested for lupus, the result may show positive even though that patient does not actually have lupus. For this reason, it is important for patients to remind their doctors they are receiving IG therapy. When necessary, IG therapy can be stopped if a patient has a critical need to be tested for something that would be affected by it. Of course, the risk-benefit ratio of stopping IG therapy should be evaluated.

3) Some patients wonder if they can contract diseases from IG therapy since it is a blood product. However, the incidence of contracting an infection from IG therapy is substantially low since the processes used to make and purify the products are highly effective.

**Patients are prescribed IG therapy for a variety of reasons, and each patient will be affected differently by it.**

**It Takes Time!**

When starting IG therapy, the brand, dose, length of infusion and recovery times are different for everyone. It may take several infusions to become fully comfortable with IG therapy, but the process gets easier with time.

Understandably, IG therapy can seem scary, overwhelming and complicated, so minimizing patient fears and uncertainties is essential. Patients should always ask a doctor or pharmacist about any questions or concerns. And, drug companies can also answer product-specific questions. Happy infusing!

**References**


**SURAYYAH MORRIS, PharmD,** an autoimmune small fiber neuropathy patient. As a medication therapy management (MTM) and pain management specialty pharmacist, she enjoys supporting patients with chronic pain and chronic conditions to help find balance and improve quality of life.
**In the News**

**SUPPORT**

IDFA Publishes Song Written By PI Patients Titled ‘I Don’t Feel Alone’

The Immune Deficiency Foundation Australia (IDFA) has published a song titled “I Don’t Feel Alone.” The song was written and performed by IDFA members at the first youth conference, “YAM JAM.” It can be viewed on YouTube at www.youtube.com/watch?v=CLkyaB75JeQ&fbclid=IwAR2w6hpBsbCXILnlQY9dqSWmvZy4hcK4WEJSFRc6OA9dxNjL-ZTCW6pwPq4.

**MEDICINES**

Grifols Doubles Co-Pay Assistance for XEMBIFY

Grifols is increasing its co-pay assistance for XEMBIFY (immune globulin subcutaneous human-kLH), the company’s first 20% subcutaneous immune globulin therapy for the treatment of patients 2 years of age and older with primary immunodeficiency disease (PI). The increase doubles the amount provided from $5,000 to $10,000 per calendar year, and eligible patients may pay as little as $0 for XEMBIFY treatment.

In addition to the increase in its co-pay assistance program, Grifols offers a patient assistance program for uninsured patients through the Xembify Connexions patient support program. For questions about the program or application process, call (844) MYXEMBIFY (699-3624). For more information, visit www.xembify.com.

**RESEARCH**

Survey Reveals Needed Improvements for State Public Health Laboratories Concerning Newborn Screen for SCIG

An online survey created by the Immune Deficiency Foundation (IDF) and the Association of Public Health Laboratories (APHL) has found state public health laboratories could benefit from making improvements in how they proceed after determining positive newborn screening (NBS) results for severe combined immunodeficiency (SCID).

APHL and IDF surveyed 53 public health NBS system laboratory and follow-up coordinators between November 2019 and January 2020 concerning three communication pathways: 1) sharing SCID NBS results with stakeholders, including healthcare providers; 2) providing SCID educational materials to both healthcare providers and parents; and 3) maintaining a follow-up program to determine outcomes for babies with SCID. They found that while primary care providers and immunologists are commonly notified by NBS programs about out-of-range SCID NBS results, less than half of NBS programs shared results with hospitals, and 16 percent of NBS programs only notified one stakeholder. According to members of the IDF’s SCID Compass team and APHL representatives who authored a paper reporting on the survey results, increasing the number of healthcare providers notified can improve access to effective counseling and appropriate care over time. “These survey results suggest that there are opportunities to expand notification of results to multiple stakeholders and to perform education to ensure patients are successfully connected to ongoing care,” said the paper’s authors.

The authors also explained that because the addition of SCID to the NBS panel is fairly recent, required of all states as of 2018, deficits in educational materials exist. Therefore, they suggested avenues to educate providers, parents and the public about SCID, including webinars, fact sheets, brochures, newsletters, videos, presentations, conference exhibits and awareness weeks. In addition, because performing long-term follow-up is challenging for NBS programs (the survey showed that less than half of all NBS programs are following patients after they receive a confirmed diagnosis of SCID), being sure to follow up with SCID cases provides better outcomes for infants, and helps identify areas in which additional resources are needed. According to the authors, the shortcomings are due to a lack of coordinated efforts and limited funding.  


LEGISLATION

Congress Extends IVIG Demonstration Project Through 2023

As part of the recently passed bipartisan omnibus, COVID-19 relief and “extenders” package, the IVIG [intravenous immune globulin] In-Home Demonstration Project, which began in 2003 and was scheduled to end Dec. 31, 2020, has been extended 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. 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.

ITP Patients with CLL More Likely to Be Treated with IVIG When Hospitalized

A study shows patients with chronic lymphocytic leukemia (CLL) hospitalized for immune thrombocytopenia (ITP) were more likely to require intravenous immune globulin (IVIG) than steroids as therapy for ITP. The retrospective cohort study, conducted since there is limited data about ITP treatment patterns and therapeutic responses in patients with CLL, used the 2016 National Inpatient Sample to analyze adults hospitalized for ITP with CLL as a secondary diagnosis based on ICD-10 codes. Primary outcomes were rate of IVIG administration, splenectomy, platelet transfusion and packed red blood cell transfusion during the same admission. A secondary outcome was length of hospital stay. Of 14,490 patients hospitalized for ITP, 255 of whom had CLL, there was a significant increase in the use of IVIG among patients with CLL and ITP. There were no statistical differences in rate of splenectomy or packed red blood cell transfusion observed between patients with and without CLL. And, there was no statistical difference in length of hospitalization between patient groups.

“Patients hospitalized for ITP with CLL were more likely to require IVIG,” said Suheil Albert Atallah-Yunes, MD, and colleagues at the University of Massachusetts-Baystate in Springfield. “This could be explained by several theories, including the need for a more rapid increase in platelet count as thrombocytopenia may be more severe due to bone marrow infiltration by CLL, immune dysfunction and/or treatment-induced thrombocytopenia. CLL patients can have hypogammaglobulinemia making them more likely to get IVIG as a treatment of choice for ITP and as immune replacement. Also, ITP patients with CLL may have less response to steroids.”

Steroids and IVIG are considered first-line therapy in ITP when treatment is indicated. Approximately 5 percent of patients with untreated CLL and 25 percent to 30 percent of patients with previously treated CLL have ITP.
No Place Like Home:
The Growing Acceptance of Subcutaneous Immune Globulin

By Keith Berman, MPH, MBA

PRIOR TO THE approval of the first licensed intravenous immune globulin (IVIG) product in 1981, IgG replacement therapy for patients with primary humoral immunodeficiency disorders (PI) was a painful and wholly inadequate ordeal. Patients had to bear frequent small intramuscular injections of 16.5% immune serum globulin (IMIG), a product whose IgG clumps and fragments caused severe anaphylactic reactions if given by the intravenous route. Poor tolerability to these repeated injections typically limited IMIG dosage, which translated into subprotective steady-state serum IgG levels and often serious recurrent bacterial infections.

Shortly before IVIG was introduced, clinicians at the National Institutes of Health (NIH) reported on their experience with yet a third approach — subcutaneous infusion of IMIG — to treat a 24-year-old woman hospitalized with cellulitis, fever and a history of sinusitis, otitis media, sepsis and pneumonia. Multiple IMIG injections to the woman’s tolerable limit had brought her serum IgG level up to only 270 mg/dL, well below the protective range. The NIH team decided to train her to self-administer small volumes of IMIG subcutaneously on a daily basis, and her sepsis and sinopulmonary infection entirely resolved. She continued her daily self-infusions

Photo courtesy of KORU Medical Systems
through a normal full-term pregnancy, even boosting her dose without incident to maintain a protective IgG level. Other patients were started on subcutaneous replacement therapy with IMIG.

The new intravenous preparations enabled patients to receive their IG replacement therapy with a single clinic visit every three weeks to four weeks, ending interest in experimentation with subcutaneous IMIG delivery. But experience has revealed that IVIG treatment can come with its own downsides:

• **Systemic adverse reactions.** These most commonly include headache, chills, flu-like symptoms, low-grade fever, urticaria, fatigue, nausea, lightheadedness, myalgia and arthralgia. Rarely, IVIG administration can result in serious adverse events that include thrombosis, renal dysfunction or failure, anaphylaxis, aseptic meningitis and hemolytic anemia.

• **Low IgG trough levels.** While a function of dose and serum half-life, IgG trough levels in the days leading up to the next scheduled IVIG infusion can potentially drop below the fully protective range.

• **Vascular access challenges.** In a small percentage of children and older adults in particular, reliably obtaining venous access for the infusion is problematic, necessitating placement of an infusion port. Unfortunately use of these devices is accompanied by risks of infection and thrombus formation.

• **Lost school/work days.** Depending on infusion time, each scheduled infusion visit requires the patient to be absent from school or work for a half day or longer.

In addition, many PI patients who will require IVIG replacement therapy over their lifetimes voice an entirely different kind of concern: the loss of autonomy or the “medicalization” of their disorder that arises from the need, every few weeks, to undergo an hours-long, nurse-supervised drug infusion procedure.

As early as the 1980s and 1990s, European investigators began to experiment with switching PI patients from IVIG to subcutaneous IG delivery. Most documented strong patient preference for SCIG, with many citing flexibility of treatment timing and independence from the need to take time away for visits to the infusion clinic. Insulin-dependent diabetics safely self-administer their drug by subcutaneous injection or through an insulin pump. Could chronic IG therapy similarly be self-infused by patients or caregivers at home? For both adults and children with PI, the answer turned out to be “yes.”

In 2006, the first IG product specifically formulated for subcutaneous administration — CSL Behring’s 16% Vivaglobin — was approved in the U.S. A few years later, Vivaglobin was replaced by Hizentra, whose 20% concentration translated into a modestly lower infused volume requirement. Over the ensuing decade, a number of other subcutaneous immune globulin (SCIG) products have followed (Table). Using a mechanical or electrically-powered syringe pump, patients can now skip the

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<thead>
<tr>
<th>Table. Polyvalent Immune Globulin Products Approved for Subcutaneous Administration</th>
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<tr>
<td><strong>Product</strong></td>
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<tr>
<td>------------------------------------------------------------</td>
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<tr>
<td>Hizentra Immune Globulin Subcutaneous (Human), 20% Liquid</td>
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<tr>
<td>HyQvia Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase</td>
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<td>CUVITRUI Immune Globulin Subcutaneous (Human), 20% Solution</td>
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<td>CUTAQUIG Immune Globulin Subcutaneous (Human), 16.5% Solution</td>
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<td>XEMBIFY Immune Globulin Subcutaneous (Human), 20% Solution</td>
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<td>GAMMAGARD LIQUID Immune Globulin Infusion (Human), 10%</td>
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1. SC: subcutaneous; PI: primary immunodeficiency disorders; CIDP: chronic inflammatory demyelinating polyneuropathy
2. GAMMAGARD LIQUID is additionally indicated for multifocal motor neuropathy (MMN) but only when administered intravenously
3. HyQvia is additionally indicated for idiopathic thrombocytopenic purpura (ITP) but only when administered intravenously
4. Takeda’s HyQvia, an innovative “facilitated” SCIG (fSCIG) product that incorporates pre-administered recombinant hyaluronidase to increase tissue permeability, permit very large volumes to be infused into just one or two sites, and reduce dosing to once every three or four weeks. In addition, two 10% IVIG products, Gamunex-C (Grifols) and Gamnagard Liquid (Takeda), are also approved for subcutaneous administration to treat PI.
regular infusion clinic visits and instead self-infuse their product at home biweekly, weekly or multiple times per week, working together with their home infusion provider to customize their regimen to adapt to their individual needs and preferences.

Numerous IVIG-to-SCIG crossover studies have reported that the large majority of adult and pediatric PI patients elect to make a permanent switch to SCIG. These are some of the most commonly cited reasons:

• “I can schedule my SCIG treatments at my own convenience.”
• “With SCIG, I don’t experience as many unpleasant reactions.”
• “I don’t have to miss work (or my child doesn’t have to miss school).”
• “I’m not reminded on a regular basis anymore that I have this genetic disease.”

Some patients on IVIG replacement therapy report a sense of malaise over the days leading up to their next infusion as the serum IgG level approaches its deepest trough level. But because smaller doses of SCIG are infused more frequently, IgG serum levels remain more stable, and trough levels don’t drop nearly as low as occurs with IVIG. Patients who experience these “rebound” symptoms prior to receiving their next monthly IVIG dose report this problem usually disappears when they switch to SCIG therapy.

But PI patients who participated in crossover studies aren’t necessarily a representative sample of the entire population on IG therapy. After all, each agreed to switch their IG therapy to SCIG in the first place, and to respond multiple times to a battery of questions about their comparative treatment experience. Is SCIG really well accepted by most patients either previously treated with IVIG or just starting out on IG therapy?

I posed this question to Leslie Vaughan, RPh, chief operations officer at Nufactor, a Specialty Pharmacy. Vaughan brings a perspective shaped by her nearly 30 years of experience in IG home infusion therapy. “Many patients, or parents of young children, understandably have some trepidation at the beginning,” she said. “They wonder, ‘Am I going to be able to do this?’ But we’ve consistently found that with education, training and support, most do fine and quickly become very comfortable with self-infusion.”

“Most patients or caregivers can become independent with SCIG administration within three visits,” added Nufactor Clinical Nurse Educator Candy Finley, RN, IgCN. “On the first training visit, the nurse completes the infusion while explaining each step,”
Finley explained. “The patient or caregiver completes each step on the second visit, with nurse assistance as necessary. Usually by the third visit, the nurse can observe and confirm that the patient is performing all steps correctly.”

Still, Vaughan pointed out that SCIG therapy is not for everyone: “Adults with very little body fat may not be good candidates. And for some patients with vision or dexterity issues, managing procedure set-up and needle insertion steps can be a problem.”

“For any patient starting or trialing SCIG therapy,” she added, “it’s important to individualize treatment. One patient may prefer to self-administer relatively large volumes of SCIG in each of a number of infusion sites in order to reduce the number of infusion sessions per week or month. Another patient may be more comfortable with placing a single needle and infusing less into that single site.” In other words, the flexibility of SCIG dosing strategy permits customization to accommodate each patient’s preferences and limitations, while still delivering the prescribed monthly gram dose of IgG.

As early as the 1980s and 1990s, European investigators began to experiment with switching PI patients from IVIG to SCIG delivery.

The Benefits of Divided SCIG Dosing

For patients on maintenance IG therapy, IVIG administration every three weeks to four weeks results in immediate (within six hours) or delayed systemic adverse reactions in 5 percent to 15 percent of infusions, affecting as many as 20 percent to 40 percent of all patients. Prehydration, premedication, slowing the infusion rate and switching to a different IVIG brand are all employed to try to avoid or at least minimize the acuity of these unpleasant systemic reactions, but the very high IgG serum concentration peak within minutes of direct IV infusion of IgG makes them all but inevitable for some patients.

By contrast, regular subcutaneous administration of IG acts in not one but two ways to moderate the peak serum level and minimize risk of nonserious systemic reactions, as well as potentially serious systemic complications, including renal insufficiency, hemolysis and, in rare instances, thrombosis and anaphylactoid reactions:

• SCIG therapy delivers a similar quantity of IgG as IVIG over a specified time period, but in smaller (or as desired much smaller) divided doses; for example, common once- or twice-weekly SCIG infusion schedules respectively split a monthly IVIG dose into three or six much smaller doses.

• Following infusion, large IgG proteins slowly transit through the lymphatic system, so the serum IgG level peaks (at a far lower concentration than with IV infusion) between two days and four days later.

SCIG administration, with its slow delivery of IgG into the circulation in small divided doses, predictably results in very low systemic reaction rates. Across five published case series evaluating SCIG therapy in PI patients, reported rates of systemic adverse reactions ranged between zero and less than 1 percent. In the largest of these studies, which monitored more than 33,000 SCIG infusions in 158 patients, the systemic adverse reaction rate was just 0.3 percent, including 100 mild and six moderate adverse events in 28 patients, with no anaphylactoid or other severe systemic reactions.

Unsurprisingly, most patients who self-infuse SCIG don’t require premedication to limit systemic side effects. But there is a trade-off: more local injection site reactions, which tend to moderate or largely resolve over time.

SCIG Usage for Autoimmune Neuromuscular Disorders Skyrockets

Over the last several years, Nufactor’s home infusion therapy program has seen well over 15 percent annual growth in numbers of PI patients self-administering SCIG. But the story of successful patient adoption of SCIG doesn’t stop there. Beginning in the 1990s, numerous patient case series, as well as placebo-controlled trials, have established the efficacy and safety of IVIG for several autoimmune neuromuscular disorders, in particular chronic inflammatory demyelinating polyneuropathy (CIDP), multifocal motor neuropathy (MMN) and myasthenia gravis (MG). Collectively, these three conditions now account for well over one-third of U.S. demand for polyclonal IG products. This is partly because many CIDP, MMN and MG patients who respond to IG require ongoing maintenance IG therapy, and partly because that maintenance dose (typically 1 g/kg
Hizentra®
Immune Globulin Subcutaneous (Human) 20% Liquid

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 a history of diseases related to the heart or blood vessels, or have been immobile for some time. Inform your physician if you are pregnant or nursing, or plan to become pregnant.

Infuse Hizentra under your skin only; do not inject into a blood vessel. Self-administer Hizentra only after having been taught to do so by your doctor or other healthcare professional, and having received dosing instructions for treating your condition.

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
- Headache
- Chest, joint, or back pain
- Diarrhea
- Tiredness
- Cough
- Rash
- Itching
- Fever
- Nausea
- 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
- Headache
- Chest, joint, or back pain
- Diarrhea
- Tiredness
- Cough
- Rash
- Itching
- Fever
- Nausea
- 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)

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.

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.
every three weeks to four weeks) exceeds the average PI dose by more than two-fold.

But while newly diagnosed hypogammaglobulinemic PI patients and their physicians can elect to start right away with SCIG replacement therapy in lieu of IVIG, this is not the case for patients prescribed IG therapy for their autoimmune neuropathy. CIDP is a good example. Because only roughly one-half of patients adequately respond to IG therapy,14 clinicians start with a trial of IVIG to determine whether it results in improvement in their disability score. If it does, and ongoing maintenance treatment is required to sustain the therapeutic benefit, SCIG may be considered as an option for patients who qualify.

Similar to the experience with PI, small divided SCIG doses and slow lymphatic transit also appears to sharply reduce both the number and severity of the systemic reactions in patients with inflammatory neuropathies on high-dose IG therapy. Two of its most common side effects — headache and nausea — were examined by Danish investigators in 59 patients with CIDP, MMN or post-polio syndrome treated with IVIG, and 27 CIDP and MMN patients treated with SCIG. In the SCIG group, headache reached a median peak value of just 1 (range 0 to 13 on a 0-to-100 visual analog scale) on day 6, versus a median peak value of 11 (range 0 to 96) in the IVIG group on day 4. A similar dichotomy was seen with reported nausea, again favoring SCIG. Just as importantly, the peak severity experienced by any patient was also far lower in the SCIG group.15

The same advantages that have made SCIG so popular within the PI patient community equally apply for patients prescribed maintenance IG therapy for their neurological disorder. Between 2015 and 2019, NuFactor’s neurological disease patient population on maintenance SCIG therapy has climbed 70 percent annually. The company appeared to be on track for similar growth in 2020.

An Option to Consider Amid the COVID-19 Pandemic

As the COVID-19 pandemic continues, patients with risk factors for severe COVID-19 disease are, in particular, being encouraged to minimize their exposure to others in the community. PI patients obviously qualify, as do many autoimmune neurological patients on IG therapy because of age, comorbid conditions or concomitant immune suppressive medications such as rituximab, azathioprine or methotrexate.

Home SCIG therapy thus offers yet one more very real advantage over regular clinic visits for an IVIG infusion: a means to minimize risk of COVID-19 exposure risk. As some infectious disease epidemiologists are now suggesting that it may be years before the COVID-19 outbreak is completely behind us, there may be no better time for clinicians who prescribe maintenance IG to take a fresh look at which of their patients might be appropriate for SCIG therapy.

References


KEITH BERMAN, MPH, MBA, is the founder of Health Research Associates, providing reimbursement consulting business development and market research services to biopharmaceutical, blood product and medical device manufacturers and suppliers. He also serves as editor of International Blood/Plasma News, a blood products industry newsletter.

Numerous IVIG-to-SCIG crossover studies have reported that the large majority of adult and pediatric PI patients elect to make a permanent switch to SCIG.
EACH YEAR SEEMS to usher in varying degrees of uncertainty regarding availability of immune globulin (IG). With many people’s lives dependent on IG, any shortage — or mere rumors of a shortage — can cause anxiety for patients and healthcare professionals. John Boyle, president and CEO of the Immune Deficiency Foundation (IDF), explains whether an anticipated scarcity of this precious drug is possible and, if so, why.

BSTQ: Is there an expected shortage of IG, and what would cause this?

Boyle: Based on the information our team at IDF has gathered, we anticipate some degree of IG shortage due to a drop in plasma donations at plasma collection centers. When the pandemic first occurred, all plasma collection centers had to alter their operations to ensure necessary social distancing and safety protocols were in place for donors and center staff. A small number of collection centers even closed temporarily. Added to that, there was reportedly confusion in some municipalities about whether collection centers could remain open even though they had been deemed essential by the Department of Homeland Security. But the greatest factor contributing to a shortage is the willingness of people to donate during a pandemic. Although donors are compensated for their time, for many, the time involved, the logistical challenges of safely getting to a plasma center, the perceived risk and other factors have shifted the risk/benefit calculations. Consequently, donations dropped starting in mid-March, and while there has apparently been significant recovery, the ongoing state-by-state spikes in COVID-19 cases mean there’s no getting back to business as usual just yet. Even with most centers operating at capacity, there are still fewer donations.

Since it takes approximately nine months to manufacture plasma-based therapies from raw plasma, we anticipate a nine-month lag time between the decrease in donations of source plasma and probable therapy shortages. Furthermore, since the supply and demand levels for source plasma were perilously
close even when source plasma collection was at an all-time high prior to the pandemic, we’re very concerned about the availability of IG beginning in January 2021.

**BSTQ:** What is being done to address the anticipated shortage of IG?

**Boyle:** IDF is galvanizing efforts to raise awareness of and encourage plasma donation, as well as to celebrate plasma donors as the heroes they truly are. We just launched our new Plasma Heroes campaign, and we are eager to see the positive impact it will have on donation levels in the short and long term.

Plasma collection and fractionation companies are opening source plasma collection centers around the United States as fast as they can, and happily, it appears the U.S. Food and Drug Administration (FDA) is working with them to minimize unnecessary barriers. Additionally, the executive and legislative branches of the federal government are addressing plasma-related issues. While they are primarily focused on convalescent plasma as a potential COVID-19 therapy, any interest in plasma serves as a “rising tide that lifts all boats” when it comes to encouraging people to donate plasma.

**BSTQ:** What are the pertinent statistics regarding plasma? For example, how much is the need for plasma outpacing supply?

**Boyle:** Unfortunately, a precise measurement of plasma supply and demand is not easy to ascertain since source plasma is collected and plasma-based products are manufactured by several different companies, each of which has its own data. And, while there are some useful aggregate data sets that exist such as those provided by the Plasma Protein Therapeutics Association (PPTA), there is no comprehensive repository for tracking supply and demand.

As a patient advocacy organization for people with primary immunodeficiency diseases (PI), IDF doesn’t have access to data to track the number of people dependent on plasma-based treatments for other medical conditions. However, based on surveys of our PI patient community, as many as 50,000 people in the United States with PI require plasma-based products to remain healthy and alive. But, there are numerous diseases treated with plasma only temporarily. The difference between those and PI patients is treatment for PI is lifelong and lifesaving. PI patients simply can’t live without it.

**BSTQ:** Are there alternatives to plasma for PI patients?

**Boyle:** There are no alternative treatments for PI patients. The IG infusions they receive are lifelong and lifesaving, and receiving IG is truly a life-or-death matter.

**BSTQ:** While this is a controversial issue, it has been rumored pharmaceutical companies sell plasma to researchers and for-profit agencies. If there is a plasma-for-sale loophole, is it contributing to plasma shortages, and are efforts being made to close the loophole?

**Boyle:** Classic blood donation and source plasma donation serve different purposes and populations, so I don’t think there’s a loophole to close, per se.

The classic blood donation system essentially serves everyone in the U.S., and since blood can be collected easily in almost any physical setting, it is easy to meet existing needs. Also, because the lifesaving nature of blood is well understood by the public and the volumes needed have historically been collected without incentivizing donors, no additional compensation has been needed. Additionally, the need for whole blood donations has decreased over time because of blood management in surgery and other areas of medicine.

The source plasma donation system serves a comparatively small population: primarily those who have rare and chronic diseases who require plasma-derived therapy for survival. More than 100 source plasma donations are needed to treat one person with a PI for one year, and more than 1,000 donations are needed to treat those with other conditions. Experience has shown that without incentivizing plasma donors such as compensating them for their time, not enough people will go to the dedicated (and highly regulated) plasma centers to donate. Additionally, more and more people who need these therapies are diagnosed each year, and new uses for plasma-derived therapies are constantly being discovered. So, unlike the need for whole blood, the need for plasma and its component proteins is increasing each year.

In short, on one hand, the number of willing donors needed for whole blood donations is adequate. On the other hand,
the number of willing donors needed for plasma donations to treat the growing population whose lives depend on plasma-derived therapies can be met only by taking measures such as compensating donors for their time.

Because the need for plasma is so great, my understanding is just about every drop of source plasma collected becomes part of the plasma therapies. I believe the rumors you are referring to concern the practice of nonprofit blood collection organizations that then sell what’s known as recovered plasma to plasma fractionation companies. Some of these companies purchase recovered plasma to supplement what they collect through source plasma centers. And, while this may be surprising to some, there’s nothing inherently problematic with that as far as I can see. Recovered plasma helps to fill a gap needed to develop plasma therapies. It’s all used for therapeutic use: saving lives.

Unfortunately, the disconnect between what is assumed and what is actual about blood and plasma collection generates alarm among those unfamiliar with it. People assume source plasma donors are being taken advantage of by a villainous plasma industry. Consequently, conversations surface about bioethics and donor safety that completely ignore prejudice or personal politics. Those conversations hijack the fact that there are people who rely on plasma-derived therapies. Since the process of creating plasma-derived therapies from source plasma is a complicated process and requires a donor to commit to regular, consistent donation, the utopian ideal of people donating plasma at levels that meet therapeutic needs with no incentive ends up failing each and every time. Canada and most of Europe are examples of this.

**BSTQ:** Are there misconceptions regarding a plasma shortage?

**Boyle:** There have been several plasma shortages over the decades that the PI community has dealt with, and each has its own unique causes. The most common misconception right now is caused by confusion about whole blood donations, convalescent plasma donations from people who have recovered from COVID-19, and source plasma donations used to make plasma-based therapies such as IG.

Whole blood, not source plasma, is donated at the Red Cross, and whole blood is not used to create plasma-based therapies. Convalescent plasma from COVID-19 patients only helps COVID-19 patients. Source plasma is collected only at certified collection centers to produce IG and other plasma therapies.

We hope the conversation and interest that surrounds convalescent plasma will help raise awareness for the importance of plasma donation in general. It’s one of the many reasons we’ve launched the Plasma Heroes initiative.

**Mitigating the Plasma and IG Shortage**

Boyle and IDF’s indefatigable efforts to ensure access to IG for those dependent upon it are reassuring to patients and healthcare professionals. As reported in a *BioSupply Trends Quarterly* plasma update, other organizations, including PPTA, are working with IG manufacturers to assist healthcare providers obtain specific products needed by patients. In addition, FDA is working to mitigate IG supply and is exploring ways to improve the manufacturing yield of IG products. The agency is also encouraging healthcare providers, hospitals and medical systems to proactively devise an evidence-based approach to deciding which patients will receive priority treatment. Beyond this, FDA has suggested hospitals and other medical systems consider a second IG product contract to improve resilience during and after the shortage.1,2 While challenges in access will almost certainly remain due to life’s unpredictability, those who strive to overcome the obstacles are, thankfully, steadfast in their work.

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

**References**


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
Taking Advantage of Telehealth Services

A few tips can help patients obtain care via telehealth video visits to avoid the risks of going to a provider’s office.

By Jim Trageser

THE ADVANCEMENT of telemedicine may be one of the pandemic’s few silver linings for the healthcare community. Telehealth is similar to telemedicine, but it is more comprehensive since it also includes nonclinical services. In its simplest definition, telehealth is the use of electronic devices and telecommunication technologies to extend care and/or interact with healthcare providers when patient and provider are in different locations. Services might include remote patient monitoring (e.g., a wearable device that tracks heart rate and blood pressure), secure messaging (e.g., email) or live phone or video chats. This article will focus solely on the latter: visits performed via live video.

Rationale for Telehealth

Without a doubt, many healthcare visits are best performed in person, and in fact, some healthcare services can be provided only in person. However, during this past year, the medical community has been discovering new ways to perform services via telehealth that wouldn’t have been considered feasible prior to the pandemic. For some, including those living with a primary immunodeficiency disease or other condition that makes them increasingly vulnerable to infection, home is often the safest place to be, and telehealth reduces the risk of leaving a controlled environment to visit a healthcare provider’s office.
Healthcare visits that might effectively be performed by telehealth include:

- Wellness checks and other general healthcare visits
- Medication consultations
- Home health and hospice visits
- Nutrition counseling
- Mental health counseling
- Eye exams
- Dermatology visits
- Urgent care and emergency department visits
- Nursing facility initial and discharge visits
- Therapy services (physical therapy, occupational therapy and speech-language therapy)

Although this list is not exhaustive, it does provide a framework of the scope of services that can be performed via telehealth. Even pets can be examined and treated via veterinary telehealth!

The University of Michigan National Poll on Healthy Aging 2020 reports that, “From 2019 to 2020, there was a substantial increase in the proportion of older adults who reported that their healthcare providers offered telehealth visits. In May 2019, 14 percent of older adults said that their healthcare providers offered telehealth visits, compared to 62 percent in June 2020,”¹ a number that has most certainly increased since then, particularly because providers for many of the services mentioned can be reimbursed for a telehealth visit at the same rate as an in-person visit.

To increase access to telehealth, and as a “good faith” provision during the COVID-19 public health emergency, federal waivers allow healthcare providers to use common tools like Zoom, Skype, Facebook Messenger video chat, Google Hangouts video and Apple FaceTime to interact with patients and clients. However, federal officials warn providers to not use any public-facing platforms for services, which could potentially be viewed by others (e.g., Facebook Live, TikTok, YouTube live stream).

Getting Started

So, where does someone interested in telehealth services start? The best first step is to call a healthcare provider and ask about the options. Several key questions include:

- Are telehealth services a good alternative for your specific situation?
- Will your insurance pay for telehealth services?
- What technology requirements exist for patients/clients to participate in a telehealth visit?
- How you can schedule a visit?

Medicare and Medicare Advantage plans will pay for many, although not all, telehealth services during the COVID-19 public health emergency. Medicaid and private insurance plan coverage, however, vary widely by state and plan, respectively.

Sometimes calling the health insurance carrier directly can be a good way to find a telehealth provider. The carrier can answer questions about coverage and should be able to help find providers with telehealth options. Many insurance companies already have their own web and/or app-based portals to access telehealth triage and primary care services, or to communicate with an assigned case manager.

There are also a growing number of on-demand telehealth options on the market, some of which are covered by health insurance and others that must be paid out-of-pocket. Those interested in exploring these services can visit www.techhealthdirectory.com, a site developed by the Consumer Technology Association and the American Telemedicine Association to help consumers and healthcare providers find digital health technologies. Beware, the myriad of choices can be dizzying!

Individuals without health insurance or an established healthcare provider may still be able to find telehealth options through a local community health center. Health centers provide services to patients regardless of their ability to pay, and when services are charged, they are sliding-scale fees. Local health centers can be found at www.findahealthcenter.hrsa.gov.

Finally, and particularly given the stress the pandemic has produced, the Substance Abuse and Mental Health Services Administration (SAMHSA) is worth mentioning. SAMHSA’s national helpline is a free confidential service for individuals and families facing mental and/or substance use disorders. The treatment referral and information service, and similar government programs at a state or local level, have been a lifeline for thousands of people struggling with increased anxiety and depression related to the pandemic and its consequences (e.g., social isolation, unemployment, illness, fear and uncertainty). The SAMHSA healthline is available 24/7 365 days a year by calling (800) 662-4357 (or for the hearing impaired: TTY (800) 487-4889).

Preparing for a Telehealth Video Visit

A computer, tablet or smart phone with audio-video capabilities and an Internet connection is all that’s needed for a live telehealth visit. For those who don’t have these
XEMBIFY is a 20% subcutaneous immune globulin (SCIG) replacement therapy used to treat primary humoral immunodeficiency disease (PI) in patients 2 years of age and older.

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References:

Please see Important Safety Information and brief summary of full Prescribing Information on adjacent pages.
Important Safety Information

What is XEMBIFY®?
XEMBIFY® (immune globulin subcutaneous human–klhw) is a 20% immune globulin used in the treatment of primary humoral immunodeficiency disease (PIID) in patients 2 years of age and older. XEMBIFY is for subcutaneous administration only.

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS
- Thrombosis (formation of blood clots within blood vessels) may occur with immune globulin products, including XEMBIFY. Before you take XEMBIFY, talk to your doctor if you:
  - Are older
  - Are sedentary (need to lie down or sit down) for long periods of time
  - Are taking estrogen-containing medicines (birth control pills, hormone replacement therapy)
  - Have a permanent intravenous (IV) catheter
  - Have hyperviscosity of the blood (diseases such as multiple myeloma or other causes of elevated proteins in the blood)
  - Have cardiovascular (heart) problems or previous history of stroke

- Thrombosis may occur even if you don't have any risk factors
- If you are at risk of thrombosis, your doctor may prescribe XEMBIFY at the minimum dose and infusion rate. Make sure you drink plenty of fluid before taking XEMBIFY. Make sure your doctor is checking you regularly for signs and symptoms of thrombosis and is checking your blood viscosity if you are at risk of hyperviscosity

Who should not use XEMBIFY?
- XEMBIFY should not be used if you have had a severe allergic reaction to human immune globulin, or if you have been told by a doctor that you are IgA deficient and have developed antibodies to IgA and hypersensitivity after exposure to a previous plasma product

What are possible serious side effects of XEMBIFY?

- Hypersensitivity. Severe allergic reactions may occur with immune globulin products, including XEMBIFY. If you have a severe allergic reaction, stop the infusion immediately and get medical attention. XEMBIFY contains IgA. If you have known antibodies to IgA, you may have a greater risk of developing potentially severe allergic reactions
- Aseptic meningitis syndrome (AMS). Aseptic meningitis is a non-infectious inflammation of the membranes that cover the brain. It causes a severe headache syndrome, which may occur with human immune globulin treatment, including XEMBIFY. If you are showing signs and symptoms of AMS, your doctor may conduct a thorough neurological evaluation including spinal tap (sampling fluid which surrounds the spinal cord) to rule out other causes of meningitis. Stopping human immune globulin treatment has resulted in the end of signs and symptoms within several days. Treatment may include analgesics (pain medicines) and/or a special procedure known as a "blood patch" to stop headache
- Kidney problems or failure. Kidney problems or failure may occur with use of human immune globulin products, especially those containing sucrose (sugar). XEMBIFY does not contain sucrose. If you have kidney disease or diabetes with kidney involvement, your doctor should perform a blood test to assess your hydration level and kidney function before beginning immune globulin treatment and at appropriate intervals thereafter. If your doctor determines that kidney function is worsening, they may discontinue treatment
- Hemolysis. Your doctor should monitor you for symptoms of hemolysis (destruction of red blood cells causing anemia, or low red blood cell count). If your doctor suspects hemolysis, they should perform additional tests to confirm
- Transfusion-related acute lung injury (TRALI). TRALI is a rare but serious syndrome characterized by sudden acute respiratory distress following transfusion. If your doctor suspects TRALI, they will monitor you for any other lung issues. TRALI may be managed with oxygen therapy
- Transmissible infectious agents. Because XEMBIFY is made from human blood, it may carry a risk of transmitting infectious agents such as viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent. No cases of transmission of viral diseases or CJD have been associated with the use of XEMBIFY
- Interference with lab tests. Because XEMBIFY contains a variety of antibodies, blood tests to determine antibody levels may be falsely elevated. Be sure to tell your doctor or lab technician that you are using XEMBIFY

What are other possible side effects of XEMBIFY?
- In clinical studies of XEMBIFY, some patients experienced local side effects (at the injection site) including pain, redness, puffiness, bruising, nodules, itching, firmness, scabbing and swelling at the site on the skin where the injection occurred. Some patients experienced non-injection-site side effects including cough and diarrhea.
- Use of XEMBIFY may interfere with the immune response to virus vaccines, such as vaccines for measles, mumps, rubella and varicella. Tell your doctor you are taking XEMBIFY before getting vaccinations

Please see brief summary of full Prescribing Information on the following page.

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.
XEMBIFY™

XEMBIFY (immune globulin subcutaneous, human – klhw) 20% solution

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use XEMBIFY safely and effectively. See full prescribing information for XEMBIFY.

XEMBIFY (immune globulin subcutaneous, human – klhw) 20% solution

Initial U.S. Approval: 2019

WARNING: THROMBOSIS

See full prescribing information for complete boxed warning.

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

- For patients at risk of thrombosis, administer XEMBIFY at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

INDICATIONS AND USAGE

XEMBIFY™ (immune globulin subcutaneous, human- klhw) is a 20% immune globulin solution for subcutaneous injection indicated for treatment of Primary Humoral Immunodeficiency (PI) in patients 2 years of age and older.

DOSE AND ADMINISTRATION

For subcutaneous infusion only.

Before switching to XEMBIFY, obtain the patient’s serum IgG trough level to guide subsequent dose adjustments.

Dose

- Switching from immune globulin intravenous (human), 10% (IVIG) to XEMBIFY: calculate the dose by using a dose adjustment factor (1.37)
- Weekly: Begin XEMBIFY one week after last IVIG infusion.
- Establish initial weekly dose by converting the monthly (or every 3 weeks) IVIG dose into an equivalent weekly dose and increasing it using a dose adjustment factor (1.37).

Initial weekly dose (grams) = Prior IVIG dose (in grams) × 1.37

- Frequent dosing (2-7 times per week): Divide the calculated weekly dose by the desired number of times per week.
- Switching from immune globulin subcutaneous (human) treatment (IGSC): Weekly dose (grams) should be the same as the weekly dose of prior IGSC treatment (grams).

Administration

Infusion sites: up to 6 infusion sites simultaneously, with at least 2 inches (5 cm) between sites avoiding bony prominences. Rotate sites for each administration.

CONTRAINDICATIONS

- Anaphylactic or severe systemic reactions to human immunoglobulin or inactive ingredients of XEMBIFY such as polysorbate 80.
- IgA deficient patients with antibodies against IgA and a history of hypersensitivity.

WARNINGS AND PRECAUTIONS

- Hypersensitivity and anaphylactic reactions may occur. IgA deficient patients with antibodies against IgA are at greater risk of developing severe hypersensitivity or anaphylactic reactions.
- Aseptic Meningitis Syndrome (AMS) may occur within two days of treatment.
- Monitor for renal function in patients at risk for renal failure.
- Hemolysis can develop. Risk factors include high doses and non-O blood group. Closely monitor for hemolysis and hemolytic anemia.
- Monitor patients for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).
- XEMBIFY is made from human plasma and may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.
- Passive transfer of antibodies may confound serologic testing.

ADVERSE REACTIONS

The most common adverse reactions in ≥ 5% of subjects in the clinical trial were local adverse reactions including infusion site erythema (redness), infusion site pain, infusion site swelling (puffiness), infusion site bruising, infusion site nodule, infusion site pruritus (itching), infusion site induration (firmness), infusion site scab, infusion site edema, and systemic reactions including cough and diarrhea.

To report SUSPECTED ADVERSE REACTIONS, contact Grifols Therapeutics LLC at 1-800-520-2807 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS

The passive transfer of antibodies may transiently interfere with the response to live virus vaccines, such as measles, mumps, rubella, and varicella.

USE IN SPECIFIC POPULATIONS

Geriatric: In patients over 65 years, do not exceed the recommended dose and infuse XEMBIFY at the minimum rate practicable.

DOSE FORMS AND STRENGTHS

XEMBIFY is a solution containing 0.2 g/mL (200 mg/mL; 20%) protein solution for subcutaneous infusion.

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Revised 7/2019
devices, COVID-19 Medicare waivers allow for most visits to be performed via audio only during the public health emergency. However, there are some obvious limitations for any service that requires a visual physical inspection.

Healthcare providers will send instructions for telehealth visits. Many providers use specialized platforms that can be easily and securely accessed through a private link at the time of the scheduled appointment. Others may still be using other commercial tools like Zoom or Google Hangouts video, which are permitted for use by the Centers for Medicare and Medicaid Services (CMS) during the public health emergency. Regardless of the choice of technology, patients should discuss with their provider questions or concerns about how to use it and whether it protects their privacy.

There are a few things individuals can do before starting a video visit with their healthcare provider that will make the time more productive. Following are the U.S. Department of Health and Human Services (HHS) telehealth site’s recommendations:

• Choose a spot with plenty of light. If using the camera on a phone, try turning on the flash if necessary.
• Make sure the camera is stable. This will be easier if using a computer or laptop. To keep a phone steady, prop it up on a desk or table.
• Get comfortable. It’s easier to focus on the visit when a patient’s body is comfortable. This is another reason to prop up the phone so it doesn’t require an arm holding it in position during the entire visit.
• Wear loose clothing. If it is necessary to show the doctor something, it’s best to wear clothes that will be easy to move so the doctor can clearly see it.
• Reduce background noise. This can be tricky when there are a lot of people in the house! But if possible, a quiet activity for the kids — or roommates — in a separate room should be planned.
• Close other applications. Some applications will slow down an Internet connection. And even if they don’t, closing them will cut down on distractions.

The Future of Telehealth

With the rapid development of technology and its applications during the past decade, telehealth in its various forms had already begun its emergence from almost stagnant growth over the past century. However, the prevalence of its use and extent of its adoption was nothing like we’ve seen in just the past year due to COVID-19.

CMS agrees with most healthcare providers, tech companies and public officials that whatever direction telehealth takes in the future, it won’t be backward. Part of the discussion in the year ahead will be which of the temporary telehealth measures in effect during the COVID-19 public health emergency should be made permanent; what guidelines and restrictions need to be developed to set limitations, if any, on telehealth’s use; and how technology can help more people remain in their own homes to receive healthcare and other assistance versus the alternative of institutional care in a long-term-care facility — all of which can potentially save healthcare dollars, improve patient/client satisfaction and help to avoid scenarios that led to some of the worst virus spreader stories of the pandemic.

For those who would like to see telehealth remain an option for care into the future, along with a mechanism to have it paid for by at least Medicare and state Medicaid plans, it’s important to keep on top of related news, particularly when Congress is in session, so representatives and senators in support of any pending legislation can be contacted. The more constituents who respond in support of or against a particular bill, the better. Grass roots advocacy is powerful! 

References

JIM TRAGESER is a freelance journalist in the San Diego area.

Teideh Health Resources
• Telehealth.gov: telehealth.hhs.gov
• Telehealth: Delivering Care Safely During COVID-19: www.hhs.gov/Coronavirus/telehealth/index.html#waivers
• Medicaid.gov Telemedicine Resources: www.medicaid.gov/medicaid/benefits/telemedicine/index.html
• Medicare Telemedicine Health Care Provider Fact Sheet: www.cms.gov/newsroom/fact-sheets/medicare-telemedicine-health-care-provider-fact-sheet
• Medicare Coverage and Payment of Virtual Services: www.youtube.com/watch?v=BspOIFnYHk&feature=youtu.be
PHYSICAL AND SOCIAL distancing has played a critical role in reducing the spread of COVID-19 as public health officials and government leaders attempt to minimize infections and save lives. However, as months of this pandemic stretch on, mandated physical distancing has led to social isolation that, for many, is a situation wrought with its own inherent health risks.

Without question, a mental and emotional toll occurs when people are asked to weigh their desire for literal survival against all the things in life that make surviving worthwhile: meals with loved ones, sporting events and concerts, access to faith communities and rituals, business and school connections, and leisure pursuits. We’ve faced mounting disappointments and frustrations as travel plans and milestone events continue to be canceled and entertainment outlets, restaurants and church closures stretch into the indefinite future. What initially seemed like a short-term sacrifice as we “got the virus under control,” has increasingly become a sustained way of life. And, as with this virus, there is still so much we don’t know while healthcare providers grapple with all the ways the pandemic has spotlighted how fundamental social contact is to our overall health and well-being.

The Impact of Loneliness on Physical and Mental Health

Loneliness is a very real side effect of social-distancing and shelter-in-place guidelines. And, while social isolation and loneliness were certainly noted societal issues pre-pandemic, these unprecedented circumstances have exacerbated an already serious public health concern. With the exception of essential workers, the pandemic
has required the rest of us to limit physical proximity and connection to those with whom we live. For the nearly 30 percent of Americans who live alone, that has meant little to no human contact for months.

Research tells us regular social interactions and a strong personal network are important to a person’s mental and physical health, resilience and longevity. The inverse is also true; loneliness can pose as grave a threat to a person’s health as smoking, obesity or substance abuse. Health concerns stemming from social deprivation include high blood pressure, sleeplessness or less restful sleep, anxiety, depression and thoughts of suicide. In addition, lack of human interaction may increase hormone levels that contribute to inflammation and weakened immunity, thereby increasing the risk of diseases.

In a recent Morbidity and Mortality Weekly Report from the Centers for Disease Control and Prevention (CDC), more than 40 percent of survey respondents experienced anxiety or depressive disorder, trauma- and stressor-related disorder, an onset or increase of substance use to cope with stress, or suicidal ideation related to COVID-19. Not surprisingly, the mental health implications of loneliness may also lead to decreases in performance or productivity. Loneliness may also affect a person’s creativity, reasoning and decision-making and may even lead to cognitive decline. Loneliness stemming from social isolation has been a public health concern in the years leading up to 2020, and COVID-19 has increased the urgency to mitigate the resulting health risks.

Isolation as a Trigger for Depression

On a global scale, life as we knew it has dramatically been transformed. According to Robert Leahy, MD, an attending psychologist at New York-Presbyterian/Weill Cornell Medical Center and a national expert in cognitive therapy, this new reality has created a perfect storm for increasing incidents of depression and anxiety disorders. “With everything going on, people can find themselves ruminating, feeling hopeless and helpless, and, ultimately, depressed,” he warns.

The National Institute for Mental Health defines depression as a common but serious mood disorder that negatively affects how you feel, think and handle daily activities such as sleeping, eating and working. Symptoms include a persistent sad, anxious or “empty” mood, irritability, and feelings of guilt and pessimism. “We are facing a national trauma, whether it’s the fear of being infected or infecting someone else, or the economic downturn, and many people are isolated,” Dr. Leahy adds.

Sadly, those who already struggle with depression and anxiety may find the situation exacerbates their feelings. Others who are used to keeping busy may suddenly find themselves alone with their thoughts and missing friends and family outside of their household. While the need to maintain social distance creates some obstacles, Dr. Leahy emphasizes there are specific steps people can take to protect their mental health and prevent depression during periods of social isolation:

- Keep a schedule. Many people have lost their familiar routines, and hours of unstructured time can create high risk factors for depression. Dr. Leahy suggests scheduling the day down to the hour. At the end of the day, check things off and make a to-do list for the next day so there is something to look forward to. Create a set of goals for the week and for the month, then make some longer-term goals. These techniques, he says, are especially important for those who are suddenly unemployed.
- Be productive with free time. Rather than thinking of isolating as restrictive, consider framing it as an opportunity to enjoy more free time. Make a list of activities to engage in such as outdoor exercise, meditation or reading books. Also, consider small household projects that typically get put off such as cleaning closets and organizing spice racks. Many people find taking up crafting or getting creative with cooking is also a way to fill down time during isolation.
- Seek human connection. Dr. Leahy suggests making a list of friends, including some who haven’t been contacted in a long time, and using the phone as a telephone rather than texting or accessing people on social media sites. Set up a regular time each day to contact people, and schedule virtual get-togethers on online platforms to talk or maybe even play games.

Finally, Dr. Leahy suggests it’s important to reframe one’s perspective: “It’s OK to feel upset and to acknowledge to yourself and to others these are difficult times. Yet, this could be an opportunity to think about what you value or really want to do with your life. If you look at this period as intentional practice of not going out to restaurants and bars, you may realize you can thrive without those routines. When the pandemic subsides and the emergency is lifted, you may find you appreciate the freedom to go to the gym or hang out with your friends even more.”
Social Isolation and Cardiac Health

According to a study reported by the American Heart Association, a heart failure patient who often feels lonely or isolated is more likely to require hospitalization than one who rarely feels socially isolated. The assessment, published in the Journal of the American Heart Association, also found a higher risk of death among those who feel very socially isolated. The study was one of the first to rigorously address the link between heart failure patients, prognosis and perceptions of social isolation. Clinical psychologist Barry J. Jacobs, PsyD, said the findings represent an important milestone. “While I have seen studies that link social isolation to decreased health outcomes, I have not seen any that show so clearly its implications for healthcare utilization and, consequently, costs,” said Dr. Jacobs, director of behavioral sciences for the Crozer-Keystone Family Medicine Residency Program in suburban Philadelphia.

The study surveyed more than 2,000 Minnesota residents diagnosed with heart failure, and although only about 6 percent of those surveyed reported high perceived social isolation, those patients were three-and-a-half times more likely than their low-perceived-isolation counterparts to die during the average follow-up time of eight months.

In another study conducted at the University Hospital in Essen, Germany, researchers found people who are socially isolated are more than 40 percent more likely to have a cardiovascular event such as a heart attack or stroke than those who were socially integrated. The study also found those who are socially isolated are almost 50 percent more likely to die from any cause. “We have known for some time that feeling lonely or lacking contact with close friends and family can have an impact on your physical health,” said study researcher Janine Gronewold, PhD. “What this study tells us is that having strong social relationships is of high importance for your heart health, similar to the role of classical protective factors such as having a healthy blood pressure, acceptable cholesterol levels and normal weight.”

Researchers went on to state that the study’s observations were of particular interest in light of current conversations on the COVID-19 isolation guidelines’ impact on health, given that social contact has been significantly restricted in most global societies. “We need to take this seriously, work out how social relationships affect our health, and find effective ways of tackling the problems associated with social isolation to improve our overall health and longevity,” added study researcher Dirk M Hermann, MD.

Suicidal Thoughts and Isolation: When to Seek Help

Everyone reacts differently to difficult situations, and social isolation is no exception. But multiple challenges and life disruptions caused by the COVID-19 pandemic can push even the mentally strong beyond their ability to cope. Depression and anxiety tend to be fed by uncertainty, isolation, stressors and loss. All of these factors have been more prevalent during the pandemic, resulting in increased risk factors for suicidal thoughts. In general, risk factors that lead to suicide include:

- Mood disorders
- Drug and alcohol abuse
- History of trauma or abuse
- Job or financial loss
- Prior suicide attempts or family history of suicide
- Access to lethal means
- Chronic disease
- Lack of access to behavioral healthcare
- Social isolation

Despite best efforts, many may find themselves feeling helpless, sad, angry, irritable, hopeless, anxious or afraid. They may have trouble concentrating on typical tasks, changes in appetite, body aches and pains, or difficulty sleeping, or they may struggle to face routine chores. When these signs and symptoms last for several days in a row, make life miserable and cause problems in daily life so it’s hard to carry out normal responsibilities, it may be time to seek help by:

- Contacting a minister, spiritual leader or someone in the faith community.
- Contacting one’s employee assistance program, if the employer has one, and get counseling or ask for a referral to a mental health professional.
- Calling one’s primary care provider or mental health professional to ask about appointment options to talk about anxiety or depression and get advice and guidance. Some may provide the option of phone, video or online appointments.
- Contacting organizations such as the National Alliance on Mental Illness or the Substance Abuse and Mental Health Services Administration for help and guidance.
- Calling a suicide hotline. In the U.S., individuals can call the National Suicide Prevention Lifeline at (800) 273-8255 or use its webchat at suicidepreventionlifeline.org/chat.

Coping with Isolation in the Age of COVID-19

The societal impact of the COVID-19 pandemic and the effects of the resulting social isolation have been felt
worldwide. Quarantine mandates and social distancing are necessary measures to prevent the virus from spreading, but it’s also important to acknowledge loneliness can and often does produce physical- and mental-health-related repercussions. Now more than ever, it’s vital for healthcare providers to stay alert to symptoms of anxiety and depression when speaking with patients, even those with no previous risk factors. Likewise, it’s critical that all of us take ownership of our own mental and physical health by proactively maintaining healthy activity levels, managing emotions and psychiatric symptoms, practicing stress-relieving techniques, and finding alternative ways to stay connected with family and friends. And, while online connections are not a replacement for physical interaction, they can be used as a bridge to get over the most pronounced feelings of social isolation. According to an article published by UK-based Priory Group, “We are in the age of the Internet, and technology can really help us to keep in touch with the people we are close to. Physical isolation does not have to mean no interactions. Technology bridges the gap. Self-isolation will give us more screen time, but if messaging gets too much, make sure you keep things verbal too. Hearing a human voice will do more for our social needs than posting or using an app.”

In addition to advising virtual connections and regular self-care, the article’s author admonishes all of us to embrace an optimistic outlook: “This will pass. Every effort is being made globally to bring this situation to a close. It will take time, but it will pass.”

References

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.
OVER THE PAST year, many of us have faced new challenges, difficulties and changes to our everyday routines. More are adjusting to working from home, which can make extra trips to the kitchen, eating in front of the computer and mindless eating habits a regular practice. If you find you are eating more meals in front of the screen, rushing your meals or are simply not paying attention to your eating habits, adopting more mindful eating practices can be beneficial. While making changes to a routine is never an easy task, especially when we are used to eating on the go or when it is convenient, tuning in to our internal hunger cues can be a first step for a more mindful eating practice. A study from the American Psychology Association found those who ate according to a certain time, ended up eating a greater amount than those who used their internal hunger cues.1

Everyone’s internal hunger signals are different, but they can include signs such as a grumbling stomach, fatigue, headaches or irritability. We can also misinterpret different signals such as thirst, stress or boredom as hunger. One way to help determine whether you are truly hungry or “mentally” hungry is to ask yourself if you would eat something like an apple or piece of celery. If these options sound appealing, it can help you determine you are ready to eat. However, if only a piece of chocolate or bag of chips sounds good, it could indicate you simply need a break from work, are bored or are facing unwanted emotions. Take the extra few seconds to tune into your body’s cues, and ask yourself if you are truly hungry.

How to Stop Mindless Eating When Working From Home

Practice these useful tips to help curb overeating during these stressful and homebound times.

By Emily Cooper, RDN

OVER THE PAST year, many of us have faced new challenges, difficulties and changes to our everyday routines. More are adjusting to working from home, which can make extra trips to the kitchen, eating in front of the computer and mindless eating habits a regular practice. If you find you are eating more meals in front of the screen, rushing your meals or are simply not paying attention to your eating habits, adopting more mindful eating practices can be beneficial. While making changes to a routine is never an easy task, especially when we are used to eating on the go or when it is convenient, tuning in to our internal hunger cues can be a first step for a more mindful eating practice. A study from the American Psychology Association found those who ate according to a certain time, ended up eating a greater amount than those who used their internal hunger cues.1

Everyone’s internal hunger signals are different, but they can include signs such as a grumbling stomach, fatigue, headaches or irritability. We can also misinterpret different signals such as thirst, stress or boredom as hunger. One way to help determine whether you are truly hungry or “mentally” hungry is to ask yourself if you would eat something like an apple or piece of celery. If these options sound appealing, it can help you determine you are ready to eat. However, if only a piece of chocolate or bag of chips sounds good, it could indicate you simply need a break from work, are bored or are facing unwanted emotions. Take the extra few seconds to tune into your body’s cues, and ask yourself if you are truly hungry.
Keep a Visual Reminder

Keeping track of how much we’ve eaten can be tricky for both more-nutritious and less-nutritious foods. Many of us utilize external cues like an empty bowl or plate or a visual reminder of how much we ate to determine how hungry or full we are, instead of our internal cues. While you adjust to listening to those cues, using visual reminders can be a helpful way to be more mindful of food portions.

Keep visible evidence of how much you’ve consumed such as empty bottles or cans, empty plates or bowls or food scraps like chicken bones or shells from peanuts or pistachios. This can help to serve as a reminder of how much you’ve consumed and keep you more mindful of listening to your internal hunger or fullness signals.

Unplug at Meal Time

Working from home can mean we spend more time at the computer, on the phone or otherwise plugged into technology for a greater part of the day. Also, sitting down to your favorite show or watching a movie can be a favorite way for many to unwind at the end of a stressful day. Eating during these times of distraction can make it harder to tune into internal cues; it is also a prime setting for mindless eating, or overeating. Many studies have shown distracted eating can negatively influence the feelings of satiety and can lead to overeating both less healthy and more healthy options.

Make it both a point and a commitment to eat all of your meals and snacks away from the computer, television and phone, and truly put all your focus on enjoying and experiencing the food in front of you. Eating without distractions can also help you tune into your inner hunger and fullness signals, and you may find it takes less food to fill you up than when you eat while distracted. You may also find you enjoy the taste and textures of your meals more since all your attention is focused on eating instead of a screen. It can be hard to break away from the screen habit, so you can always start with one meal at a time. Pick the meal you think would be the easiest to eat distraction-free and build up to eating all of your meals and snacks this way.

Eat Slowly

Eating at a slower pace goes hand in hand with a more mindful eating practice. Busy work schedules and dealing with a work-from-home life can mean meals are more rushed, on top of eating while distracted. Once you make a commitment to eating without distractions, focus on eating both meals and snacks at a slower pace as well. It can take up to 30 minutes for the signals of satiety to travel from your stomach to your brain telling you you’re full. When we rush eating, we aren’t giving our bodies enough time to process the amount of food we are consuming, and it can increase the chances of overeating.

Take as much time as your schedule allows to enjoy meals away from the screen. Putting your fork down between bites can be an easy way to slow down the pace of your meal. If you are usually prone to choose larger portions or second helpings, take a smaller portion at first, and give yourself 10 minutes to 15 minutes before going for more. This can be enough time for the feeling of satiety to kick in, and you may find you don’t need an extra serving. If after this pause you find you are still truly hungry, listen to your internal cues and enjoy your extra serving more mindfully and slowly.

Keep Healthier Choices Visible

It can be all too easy to go for a handful of chips, candy or snack foods when they are easily accessible. Swap these foods out by keeping healthier choices in plain sight. One easy way to do this is to keep a bowl of fresh fruits on your countertop or table. This can be a simple reminder to make a healthier choice if you find yourself coming to the kitchen for a snack break.

Many less-healthy choices are ready-to-eat and convenient, which makes it easier to gravitate toward them. Instead, make healthier choices the easy choice. Chop fresh vegetables into snack size sticks, or buy prechopped vegetables for an even easier option, and keep them in your refrigerator. Or, cook sources of protein ahead of time by baking chicken, hard-boiling eggs or roasting salmon. This can make putting together a healthy and balanced meal a quick and easy option.

Keep Treats Out of Sight

On the flip side, keep treats and indulgences tucked away to deter mindless eating throughout the day. A study published in the *International Journal of Obesity* found those who had clear bowls of candy on their desks went for the candy 71 percent more often than those who had covered or solid bowls. Having foods such as candy, chips or snack foods visible and easily accessible makes it easier to impulsively go for these foods, especially when we are distracted with work or electronics.
While it is fine to enjoy these foods and treats, it can be helpful to keep them off your desks and kept in a drawer or cabinet instead. This can make the act of enjoying these foods more deliberate and intentional. Give your full focus, just as with your meals, and truly savor the moment, which can make them more satisfying as well.

**Use Smaller Plates and Glasses**

The size and shape of the plates, bowls and cups we use can play a big role in how much we consume. Brian Wansink, a psychologist and author of the book *Mindless Eating: Why We Eat More Than We Think* and a pioneer in the study of mindless eating, identified many ways plate and glass size influences how much food we eat. He found using larger plates and cups can lead to a 30 percent increase in the amount consumed.4

It’s natural to want to fill up a plate with food, no matter the size. Swapping out larger plates for smaller ones can be an easy way to be more mindful of portion sizes. This, in conjunction with eating without distractions and more slowly, can help make you more mindful of fullness signals. It can also lead you to discover you need less food than you thought to fill you up. If you regularly drink sodas, juices or other calorie-laden beverages, switching from a tall and thin glass to a short wide glass can cut back your portions of them by up to 57 percent, even if both glasses hold the same amount of liquid.5

**Take Foods Out of Packaging**

Whether you are in front of the TV, your computer or your phone, eating while distracted makes it nearly impossible to track how many servings of a food you’ve consumed. It’s not uncommon to sit down to a television show with a favorite bag of chips, popcorn or other crunchy snack only to realize you’ve reached the bottom of the bag before the show’s even over. In fact, research has shown the longer a television show, the more you are likely to eat. A study in the journal *Appetite* found participants consumed 28 percent more popcorn during a 60-minute program compared to a 30-minute program.6

If eating a snack while watching a movie or show or while you work is a must for you, portion it out. Measure out a serving or two of your snack or treat of choice, and put it in a separate bowl or plate, instead of eating straight from the package. This can make it easier to keep from mindlessly consuming more portions than you planned, while still enjoying your favorite foods in a more conscious manner.

**Avoid Buying in Bulk**

These uncertain times have led to buying many items in larger quantities. When it comes to snack foods, this may not be the best course of action for mindful eating. Research has shown doubling the amount of snacks on hand can lead to consuming 81 percent more calories compared to buying a regular amount of snacks.7 Having a stockpile of snack foods can have an abundance effect, which can lead to enjoying these foods more often. Essentially, the more you have, the more you tend to consume.

If you truly want or need to buy certain foods in bulk, make it a habit to keep them out of everyday sight or stored away. This can moderate the habit of eating more often due to the abundance mentality.

**Make Small Changes**

It can be difficult to balance working from home, daily life and making healthier choices in these trying times. However, making small changes to your eating habits can be an approachable way to make them stick, without turning them into overwhelming tasks. Work on one of these mindful eating habits at a time and give yourself some grace during these habit changes. With many of us facing a lot of challenges at once, being too hard on yourself only adds to the stress. Be gentle with yourself and give yourself time. Changes won’t happen overnight but putting attention and energy into being more mindful throughout the day with your eating habits will benefit your health and well-being in the long run.

**References**


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Let’s Talk!

Profile: Laurie Bump

By Trudie Mitschang

Trudie: Jonah was born with SCID. When did he first present with symptoms, and what were they?

Laurie: Jonah first presented symptoms of SCID at 3 and a half months of age. We did not realize it was SCID at the time, but he began to become very ill with pneumonia, and it was not getting any better with treatment. After he was diagnosed with SCID, we discovered he had rotavirus and respiratory syncytial virus, as well as pneumonia.

Trudie: Can you tell us about your journey to an accurate diagnosis?

Laurie: Unfortunately, the state of Indiana where we live did not have newborn screening for SCID at the time of Jonah’s birth. He was sick for a month and a half with pneumonia and was not showing signs of improvement. Eventually, his pediatrician told me she had no idea what was wrong with him, so I began to call around for a second opinion. Soon, a pediatrician affiliated with Norton Children’s Hospital agreed to see him. After our initial office visit, the doctor still did not know what was wrong with Jonah, but he agreed with me that it was not normal for him to be sick for so long. Jonah was also having issues with eating and weight gain, and at that time, the doctor recommended admitting him to Norton for failure to thrive. Thankfully, once we were in the hospital, he was evaluated using a wide array of tests, and Jonah was diagnosed with SCID two days later.

Trudie: What was Jonah’s initial prognosis?

Laurie: We were told that Jonah’s infections had to be addressed so he could be healthy enough to get ready for his stem cell transplant. Jonah would have to undergo conditioning that would involve chemotherapy to help his body accept the transplant. Some children with SCID continue to receive infusions of intravenous immune globulin (IVIG) throughout their lives, but our physician, William Tse, felt confident with the conditioning and transplant Jonah was receiving that his body would produce antibodies on their own. He has currently only received two infusions of IVIG since being discharged from the hospital.

Trudie: How did you meet Dr. Tse?

Laurie: Dr. Tse is the director of the pediatric blood and marrow transplant program at the Norton Children’s Hospital. He came by and spoke to my husband and me about Jonah’s condition soon after he was diagnosed. We felt very lucky to have a doctor who had treated other children with SCID and knew so much about such a rare disease.

Trudie: Can you tell us about the steps that led to Jonah getting a stem cell transplant?

Laurie: Jonah was matched with a stem cell donor through a program called Be the Match. His cells that were transplanted were donated from cord blood. Jonah had other matches as well, but cord blood was chosen because it was quickly available for transplant. Jonah underwent conditioning for 10 days prior to the transplant, which included chemotherapy to prepare his body to accept the cells. He was 7 months old when he had the procedure.

WHEN LAURIE Bump’s son, Jonah, was diagnosed with severe combined immunodeficiency disease (SCID) as an infant, his only chance of survival was a stem cell transplant. Fortunately, Jonah received the transplant at Norton Children’s Hospital in Louisville, Ky., thanks to an anonymous donor. A few years later, Jonah and his family paid a surprising and heartwarming tribute to the amazing doctor who played an instrumental role in his care and recovery.
Trudie: What can you tell us about the stem cell transplant?

Laurie: The procedure itself lasted about an hour. Jonah had a few nurses monitoring his vital signs and his transplant nurse pushed his cells into his central line by hand. Dr. Tse was there to watch the procedure, as were my husband and I.

Trudie: You’ve mentioned in other interviews that Dr. Tse has become like family. How so?

Laurie: When you are isolated for three months in the hospital, the nurses and doctors become extended family and friends. Some days, they were the only faces that I saw. Dr. Tse always went above and beyond to take care of Jonah. He stopped by when he was off work to check on him and even brought me a plate of food when he found out I hadn’t eaten. He cares for his patients, but he also cares for the whole family.

Trudie: How has Jonah’s health and prognosis improved?

Laurie: When Jonah was initially released from the hospital, he took 12 medications as often as two to three times a day. He also had a feeding tube and was given intravenous nutrition. Now, almost two years later, Jonah is eating like a normal toddler (although he’s still not a huge veggie fan), and he does not take any medication besides the occasional allergy medicine.

Trudie: Many 2-year-old boys dress up as Superman or Spiderman for Halloween. How did you decide on the doctor costume?

Laurie: Jonah is really into pretend play right now, and he recently received a doctor kit that he loves. It felt like the right fit for Jonah to dress up as Dr. Tse, who is a hero to our family. His costume included a white coat and Dr. Tse’s signature blue Oxford shirt that he always wears underneath the coat. We also added a hospital name tag that said “Tse Jr.” When the costume was complete, I texted the picture to one of Dr. Tse’s transplant nurses and asked her to relay it to him. When he saw it, he said he was honored.

Trudie: How have you maintained a positive outlook throughout this journey?

Laurie: The confidence that all the doctors and nurses had as they took care of Jonah definitely made me feel optimistic about the care he was given. I also had a lot of support and prayers from my friends and family that helped our family more than they realize.

Trudie: What advice can you offer other parents of children living with a chronic immune disease?

Laurie: I think in some ways it’s just like how being a new parent has a learning curve. I feel the same is true with having a child with a chronic immune disease. Some days are so hard, and you feel like you are failing; the pressure of trying to provide the best care you can is often overwhelming. But, over time, things get easier. Administering medication, bandage changes and mealtimes get easier, and as you become more comfortable with your child’s care, you can begin to focus on fun things like play time and sweet smiles. And, Halloween costumes!

Trudie: What are your hopes and dreams for your son?

Laurie: Jonah has a beautiful, loving personality, and he is incredibly funny. As he grows older, I hope I am able to explain to him the things he has gone through, and I hope he has a heart to give back to children who have experienced similar struggles. Last year, we started a program called “Jonah’s Jammies.” We collected pajamas in November, and we were able to supply all of the patients at Norton Children’s Hospital with pajamas for Christmas. Ultimately, I do not know where my son will go in life, but right now I’m trying my best to soak in couch cuddles, nighttime reading and rocking my toddler to sleep, things I didn’t know if I would get to experience two years ago.

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.
SOMEBODY HAS got to call Mary Poppins out! A spoonful of sugar does not help the medicine go down. At least not the medicines those of us with immune deficiencies have to choke down. When I was a child, it was a battle of wills between my parents and me. “You’ll sit there, and you won’t get up until you’ve taken your medicine, Whitney,” they told me. My young will was strong, and after sitting some days for hours, my mom or dad would finally sit beside me and hand me each medication one by one, encouraging me to partake of my mini-pharmacy.

Then, one day, my 8-year-old self came up with a brilliant plan. When mom and dad leave the room, I can wrap my medicine in a napkin and throw it away! They will never know. And that’s what I did for two weeks. I looked over my shoulder to make sure the coast was clear, I poured out the juice in a paper cup, squirted the syringe of liquid poison into the sink, carefully wrapped my pills in a napkin, stuffed the napkin in the paper cup, and tossed it in the trash. I had a meticulous system and kept up the subterfuge for two weeks. But my conscience finally got to me while sitting in church. So, I wrote my mom a note and this is what it said:

Mom, I need to confess something to you. For the past two weeks I have been throwing my medicine away. You can punish me any way you like, but I wouldn’t believe what a “You got this!” or “I’m so proud of you!” or even “Let’s beat the bad guys!” will do for your child’s spirit. A little bit of dread will be replaced with a little bit of joy as your child looks forward to the next special message.

Incentive sticker chart. What child doesn’t like stickers or the promise of prizes? On a piece of poster board, trace your child’s name and every time he or she bravely takes the medicine, allow him or her to put three stickers on a letter. When one letter is filled with stickers, a small prize is the reward. When every letter is filled, a grand prize awaits. Your child will look at this as a game, and most children want to win.

Try one of these ideas, switch it up or come up with your own creative way to validate your child is a superstar for having to do something not so fun. The phrase the famous Mary Poppins coined may not be accurate, but you can make the second part of the song true by helping your child’s medicine go down in the most delightful way.
Mourning My Old Life to Make the New One Brighter

By Michelle Searle

IN THE CHRONIC illness community, I have heard many times it’s OK to mourn your old life — the one before you became sick and were diagnosed. But I was diagnosed as a child, so I don’t really remember an old life. However, I can now relate to this statement since it applies to our current situation amid the pandemic.

As I write this, we have been dealing with COVID-19 for about eight months. Many countries are experiencing a second wave. Where I live in Italy, cases are the highest they have ever been, and the government is trying to avoid a second lockdown. However, the majority of public schools for older children are returning to online learning; gyms, movie theaters and clubs are once again closed; restaurants and coffee shops are open only until 6 p.m. with a limit on how many people can sit at a table; masks are mandatory from the moment you step outside your home; stores limit how many people can enter, with some as few as one person at a time; and some regions have curfews. Had I heard of these restrictions a year ago, I would have thought I was reading fiction. I cannot believe this is how people have to live now, all around the world.

Many of us with chronic illness have experienced loneliness. We feel alone because our health problems are rare. We feel isolated physically and emotionally because our health problems keep us in the hospital, at the doctor’s office or at home. For many of us, having to isolate, wear a mask and avoid large groups is nothing new; but, for many others, including myself, this goes beyond the normal precautions we have taken because of our illnesses. Feelings of loneliness and isolation are at an all-time high, with no end in sight. I ache to see my family and friends again. I yearn to hug people again. I would love to stand next to somebody in a store or restaurant and not feel worried because we are too close to each other. I want to use a public bathroom and only feel mildly worried about the germs because I have an immune deficiency, yet not overly worried because of a pandemic.

I mourn for my life before COVID-19. I miss going to the gym and yoga class. I miss leaving my apartment and having only to double-check that I have my phone, keys and wallet and not my mask. I miss meeting friends on the weekends and going out to eat in the evenings. I wish I could shop with other people, instead of waiting outside for someone to walk out so I can walk in. Many are wishing they could go back to school or work. From small things such as seeing a stranger’s smile in the street to more significant things like traveling to attend a loved one’s funeral or meeting a new member of someone’s family, we are all missing things we once took for granted.

Maybe I was naive to think this pandemic would be better by now, because all I see are things becoming worse. I am trying my best to adjust and tell myself the most important thing right now is to stay physically and mentally healthy, but there are days when everything becomes too overwhelming.

I believe connections with people are important. And, while I am grateful for the technology we have today that allows us to interact with others whether they are across the street or across the globe, connections can only go so far through a screen. A screen cannot replace touches, hugs and kisses. It cannot replace the warmth and safety you feel when you are in a loved one’s arms. It cannot match the connectedness you feel when you shake someone’s hand. It cannot replicate the excitement and nervousness you feel when you meet someone new for a date and you are not sure whether to shake hands or go in for a hug. I miss the simplicity of life before, and that’s saying a lot for someone living with a compromised immune system.

I mourn for my life before, but I keep moving forward, knowing this will only make me stronger and wiser. And I know I will gain an even greater appreciation for life and all the small joys we experience in a day. I move forward knowing this period will not last forever. This too shall pass and when it does, I will see my new life again, but it will shine even brighter than it did before.

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.
OVER THE years, families of children with chronic conditions such as primary immunodeficiencies have made the decision to homeschool. This is nothing new. Historically, the risk of transmitting germs between children in school and the flexibility homeschooling offers when it comes to medical appointments and receiving treatments motivated some families to prefer homeschooling over public or in-person school for their children. But in recent months, with the ongoing COVID-19 pandemic, even more families are choosing to educate their children at home (if they have a choice in the matter) not just to keep them healthy, but to offer them more consistency during a time of constant change.

Last spring, many families were suddenly forced to homeschool their children when more than 124,000 schools closed due to COVID-19, impacting more than 55.1 million students across the country. And the impact of the pandemic continues to affect families’ school choices. When school reconvened in the fall, many parents faced a dilemma: Should they send their kids back to school or keep them home? Some opted to keep their children enrolled in their local public or private schools, even though many of those schools adopted a hybrid learning model, while others chose to switch completely to virtual/online learning.

Remote learning through the public school system. Some school districts that began the year by holding in-person classes (at least until COVID-19 infection rates require them to change models) still offer online-only or remote/distance learning options to families of high-risk children or those who feel more comfortable keeping their kids home. This online option allows children to stay enrolled in their local school district while keeping them connected with friends and teachers. There is no need to transfer transcripts or medical records, and there is very little paperwork. The teacher is usually in a school classroom and holds classes via Zoom or another online conferencing platform. With this model of at-home schooling, parents are not needed to be the teachers. They are there only to offer help and to ensure their children are safe and staying on task. When COVID-19 is behind us and things hopefully return to “normal,” this remote learning model may no longer be an option through public schools. Only time will tell which of the many changes this pandemic has brought will be temporary and which will become permanent.

Traditional homeschooling. To avoid uncertainty and constant need for adjustments this year, some families have decided to shift to full-time homeschooling, separating from their local school district and teaching their children on their own. How this looks and how each family accomplishes this depends on the specific homeschool model they choose. For families interested in traditional homeschooling, there are several options.

Homeschooling works well if at least one parent is at home and has the desire to take on the roles of teacher, principal, curriculum specialist, counselor, etc. Families going the traditional homeschool route typically bear the burden of purchasing textbooks for their children. In many situations, the parents dedicate a room of their house to school instruction complete with desks, bulletin boards and educational posters. The instruction style may vary, but many traditional homeschooling parents utilize a lecture-style teaching method,
and they have their days solidly scheduled to maintain structure.  

One benefit of traditional homeschooling is the variety of curriculum from which parents can choose. They can tailor their child’s education to meet his or her specific educational needs and future career goals, while also meeting state standards. They can choose a curriculum suited to that child’s academic strengths and interests such as one heavy on art or music courses. The flexibility to customize a child’s education based on a particular instructional philosophy or the way parents envision an ideal learning environment is one of the greatest benefits of homeschooling.2  

Families who move frequently such as those in the military or those who enjoy traveling can take advantage of the flexibility homeschooling offers. Custom homeschooling styles such as “roadschooling” or “worldschooling” have become a growing trend in at-home education. Families pack up their belongings and take their kids on the road to see and experience what they’re learning about, rather than just reading about it in a book. Roadschooling parents can integrate what they are seeing and experiencing into their child’s homeschool curriculum.3 But first, parents must be sure to consult their state’s homeschooling laws before beginning this adventurous and unconventional style of education!  

Which curriculum is best? With the many styles and schooling options available, choosing a curriculum can seem like an overwhelming task. The good news is there really is a curriculum to fit every child and family. The first step is to search for homeschool curriculum online. Parents should consider their teaching style, educational philosophy and their child’s learning preference and educational goals. To narrow down the choices further, the Homeschool Legal Defense Association (HSLDA), the nation’s largest homeschool advocacy organization, recommends these steps:4  

- Parents should talk to other homeschooling families they know. One family might have tried a certain curriculum with their kids and can tell you how it works. They may even have some curriculum left over that they could lend you so you could spend time looking at it.  
- Crowdsource your questions on Facebook. Ask local homeschooling parents if they can recommend a homeschool Facebook group, or search for a group that seems to fit your style. Join more than one group so you can find a good match.  
- Attend homeschool conferences with curriculum exhibit halls where the curriculum is on display to see and touch. Talk to the curriculum publishers in person.  
- Find curriculum reviews at online retailers like Amazon and Christianbook. com, or look up testimonials from homeschooling parents on YouTube.  
- Visit the HSLDA website (www. hslda.com) for valuable resources and to find homeschool groups in your area.  
- Online schools. Not all parents have the desire or time to act as teacher to their children. While they want their kids to learn at home, they would rather hand the actual task of teaching over to a certified teacher who can teach their children remotely.  

Many states have online, tuition-free public school options such as Connections Academy and K12. Online schooling allows students to learn at home while enjoying the benefits and support of a school program. Students are part of a class, and they have the opportunity to socialize with classmates virtually and on excursions or field trips.5  

While parents are not teachers in this model, they are still closely involved in their children’s daily education and play an important role as coaches and mentors.6 Students enrolled in K12-powered schools, for example, “adhere to state testing, school accountability and attendance policies just as brick-and-mortar schools do, and graduates earn a high school diploma.”5  

With most online public schools, there is no fee for tuition, and books and other instructional materials are free. The only cost involved is for field trips and school supplies.  

Whether it’s because of health or medical issues, the need for an alternative and flexible schedule or to maintain consistency in schooling during a year of uncertainty, there are many reasons a family may need or want to choose homeschooling. And there really is a style to fit every family and child.  

References  

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

HOT FLASHES. Drenched sheets. High fevers. Even in the midst of winter on a frigid night or during a cool day, individuals with chronic illnesses are often accompanied by an unwelcome sidekick: their personal heaters. Immune globulin (IG) therapy can be partially to blame for heat intolerance. Couple that with extreme hormonal and nerve imbalances caused by many illnesses, and it makes sense that the body’s natural climate control comes under assault.

For some patients, maintaining a temperate environment takes more effort than simply turning the AC up. But, arming themselves with an array of personal cooling devices will help make both day and night much more comfortable and a lot less dangerous.

Regulating Personal Temps
Hypersensitive to heat? Heat intolerance is common but there’s a difference between being uncomfortable when the temps hit triple digits and not being able to cool down. In normal circumstances, the human brain tells the nerves it’s time to increase sweat production, which subsequently cools down the body. But when the elements are off, this natural hot and cold balance can end up out of whack. Certain medications can prevent sweating, therefore inhibiting the body’s natural ability to cool itself. For example, hyperthyroidism, commonly caused by Graves’ disease, can result in an excess of the hormone thyroxine, which increases the body’s metabolism and leads to a rising body temperature. Or, in the case of multiple sclerosis, the protective covering of the central nervous system is damaged, leading to heat intolerance.

The Dangers of Overheating
Nearly 24 million Americans suffer from an autoimmune disease, according to the National Institutes of Health. And considering many of these illnesses and their treatments may lead to heat intolerance, keeping these individuals cool and comfortable is critical. This is because overheating is not only uncomfortable but can also lead to severe complications — from the temporary loss of vision and an elevated heart rate to confusion and loss of consciousness.

Cooling Down
Waking up in a pool of sweat is not exactly a recipe for a sweet night of slumber. Couple that with insomnia, already an issue for many IG patients, and it’s a surefire recipe for tossing and turning. However, curbing restless nights and overly hot days is possible with some preemptive measures. Avoiding heat-inducing caffeine, spicy foods and evening exercise are first on the list. Also, maintaining a cool 65-degree bedroom is critical, according to sleep experts.

Once those changes have been implemented, experts agree a bed outfitted with natural, breathable fibers is essential to combat overheating. So, feel free to purchase those linen sheets you’ve been eyeing. After all, is there a better excuse to do a little shopping than getting a good night’s sleep?
Naturally Sweet Dreams
Unlike stuffy synthetic sheets, and even cotton ones with high thread counts, the looser weave of linen results in less trapped heat, more breathability and an overall cooler snooze. Pick up a set of all-natural linen sheets from Garnet Hill and wave goodbye to those sweaty slumbers. Its 100 percent linen sheets are crafted in Portugal from European flax and are available in an array of colors and prints. $109 and up; www.garnethill.com/bedding-home/sheets/linen-sheets

Your Own Private Climate
Keep things cool in your personal space with the Embr Wave Temperature-Control Bracelet. This wearable technology allows you to control your personal temperature by touching the illuminated bar — blue for cooler and red for warmer. By cooling the skin on the wrist, the wearer will feel at least 5 degrees cooler. The adjustable stainless-steel bracelet is available in both rose and silver. $350; embrlabs.com/?rfsn=3729439.9fc2d8f

Shopping Guide to Keeping Cool

Head to the Cool Seat
A pool of sweat in your chair? Not much is worse than a sweaty warm seat, especially when you’re already overheated. But snap on the Zone Tech cooling seat cushion and the circulating air will add a breathable layer between your body and the seat. Use this versatile cooling seat in your car, office or home by simply plugging it into an AC adapter for that cooling sensation. $39.94; www.amazon.com/SE0051-Automotive-Adjustable-Temperature-Comfortable/dp/B01KTX0N68

Just Chill
When there is a need to cool down, most people head straight to the neck. Why? Because that area contains pulse points making it the ideal spot to quickly lower body temperature. Of course, a wet towel can do the trick, but unlike that soggy cloth, the MISSION Cooling Neck Gaiter cools to 30 degrees below average body temperature and stays cold for up to two hours. Just soak it, wring it out and snap it. The gaiter can also be worn in a variety of ways such as a face mask, hat or headband. $19.99; www.amazon.com/MISSION-Cooling-Gaiter-Wears-Cools/dp/B08B6GM5G6

The Little AC That Can
Stuck in an overheated office or sleeping in a stuffy bedroom? Plug in the Sharper Image Personal Evaporative Cooler and watch as both your productivity and sleep improve. Not only will this compact device cool and filter the air in your personal space, it will also humidify that dry office air. To operate, simply add two pints of tap water, and the eco-friendly evaporative cooling system will lower the temperature in spaces up to 45 square feet and operate for up to 13 hours on a full tank. $99.99; www.sharperimage.com/view/product/Personal-Evaporative-Cooler/207377

Comfortably in Control
Stop arguing over the thermostat or kicking off those bulky blankets. Sleep Number’s Dual Temp individual layer gives you total control over your bed’s temperature. Simply layer the sleeping pad on your individual side and choose from cool to warm at the touch of a button. The pad fits any mattress and will result in a 35 percent cooler or warmer bed thanks to its active air technology. $699.99; www.sleepnumber.com/products/dualtemp-layer
Ataxia Telangiectasia (A-T)

**Websites**
- A-T Children’s Project: [www.atcp.org](http://www.atcp.org)

Chronic Inflammatory Demyelinating-Polynuropathy (CIDP)

**Websites**
- GBS/CIDP Foundation International: [www.gbs-cidp.org](http://www.gbs-cidp.org)

Evans Syndrome

**Online Peer Support**
- Evans Syndrome Research and Support Group: [www.evanssyndrome.org](http://www.evanssyndrome.org)

Guillain-Barré Syndrome (GBS)

**Websites**
- GBS/CIDP Foundation International: [www.gbs-cidp.org](http://www.gbs-cidp.org)
- The Foundation for Peripheral Neuropathy: [www.foundationforpn.com](http://www.foundationforpn.com)

Idiopathic Thrombocytopenic Purpura (ITP)

**Websites**
- ITP Support Association – UK: [www.itpsupport.org.uk](http://www.itpsupport.org.uk)
- Platelet Disorder Support Association: [www.pdsa.org](http://www.pdsa.org)

Kawasaki Disease

**Websites**
- American Heart Association: [www.heart.org/HEARTORG/Conditions/More/CardiovascularConditionsofChildhood/Kawasaki-Disease_UCM_308777_Article.jsp#T12boPWE5](http://www.heart.org/HEARTORG/Conditions/More/CardiovascularConditionsofChildhood/Kawasaki-Disease_UCM_308777_Article.jsp#T12boPWE5)
- Kawasaki Disease Foundation: [www.kdfoundation.org](http://www.kdfoundation.org)
- KidsHealth: [kidshealth.org/parent/medical/heart/kawasaki.html](http://kidshealth.org/parent/medical/heart/kawasaki.html)

Mitochondrial Disease

**Websites**
- United Mitochondrial Disease Foundation: [www.umdf.org](http://www.umdf.org)
- MitoAction: [www.mitoaction.org](http://www.mitoaction.org)

Multifocal Motor Neuropathy (MMN)

**Websites**
- The Foundation for Peripheral Neuropathy: [www.foundationforpn.com](http://www.foundationforpn.com)

Multiple Sclerosis (MS)

**Websites**
- All About Multiple Sclerosis: [www.mult-sclerosis.org/index.html](http://www.mult-sclerosis.org/index.html)
- Multiple Sclerosis Association of America: [mymssaa.org](http://mymssaa.org)
- Multiple Sclerosis Foundation: [www.msfocus.org](http://www.msfocus.org)
- National Multiple Sclerosis Society: [www.nationalmssociety.org](http://www.nationalmssociety.org)

Online Peer Support
- Friends with MS: [www.friendswithms.com](http://www.friendswithms.com)
- MSWorld’s Chat and Message Board: [www.msworld.org](http://www.msworld.org)
- Overcoming Multiple Sclerosis: [overcomingsms.org/community](http://overcomingsms.org/community)

Myasthenia Gravis (MG)

**Websites and Chat Rooms**
- Myasthenia Gravis Foundation of America (MGFA): [www.myasthenia.org](http://www.myasthenia.org)

Online Peer Support
- Genetic Alliance: [www.geneticaalliance.org](http://www.geneticaalliance.org)

Myositis

**Websites**
- The Myositis Association: [www.myositis.org](http://www.myositis.org)
- International Myositis Assessment and Clinical Studies Group: [www.niehs.nih.gov/research/resources/imacs](http://www.niehs.nih.gov/research/resources/imacs)

Online Peer Support
- Myositis Association Community Forum: [tnacommunityforum.ning.com](http://tnacommunityforum.ning.com)
- Myositis Support Group – UK: [www.myositis.org.uk](http://www.myositis.org.uk)

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)

**Websites**
- PANDAS/PANS Advocacy and Support: [www.pas.care](http://www.pas.care)
- PANDAS Network: [www.pandasnetwork.org](http://www.pandasnetwork.org)
- Midwest PANS/PANDAS Support Group: [www.midwestpandas.com](http://www.midwestpandas.com)

Pemphigus and Pemphigoid

**Websites**
- The International Pemphigus and Pemphigoid Foundation: [www.pemphigus.org](http://www.pemphigus.org)

Peripheral Neuropathy (PN)

**Websites**
- Neuropathy Action Foundation: [www.neuropathyaction.org](http://www.neuropathyaction.org)

- Western Neuropathy Association: [www.pnhelp.org](http://www.pnhelp.org)
- Neuropathy Alliance of Texas: [neuropathyalliancetx.org](http://neuropathyalliancetx.org)
- The Foundation for Peripheral Neuropathy: [www.foundationforpn.com](http://www.foundationforpn.com)

Primary Immune Deficiency Disease (PI)

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

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

Scleroderma

**Websites**
- Scleroderma Foundation: [www.scleroderma.org](http://www.scleroderma.org)
- Scleroderma Research Foundation: [www.srfcure.org](http://www.srfcure.org)
- Johns Hopkins Scleroderma Center: [www.hopkinsscleroderma.org](http://www.hopkinsscleroderma.org)

Online Peer Support
- International Scleroderma Network: [www.sclero.org/support/forums/a-to-z.html](http://www.sclero.org/support/forums/a-to-z.html)

Stiff Person Syndrome (SPS)

**Websites**
- American Autoimmune Related Diseases Association Inc.: [www.aarda.org](http://www.aarda.org)
- Genetic Alliance: [www.geneticaalliance.org](http://www.geneticaalliance.org)
- Living with Stiff Person Syndrome (personal account): [www.livingwithspss.com](http://www.livingwithspss.com)
- Stiff Person Syndrome: [www.stiffpersons syndrome.net](http://www.stiffpersons syndrome.net)
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