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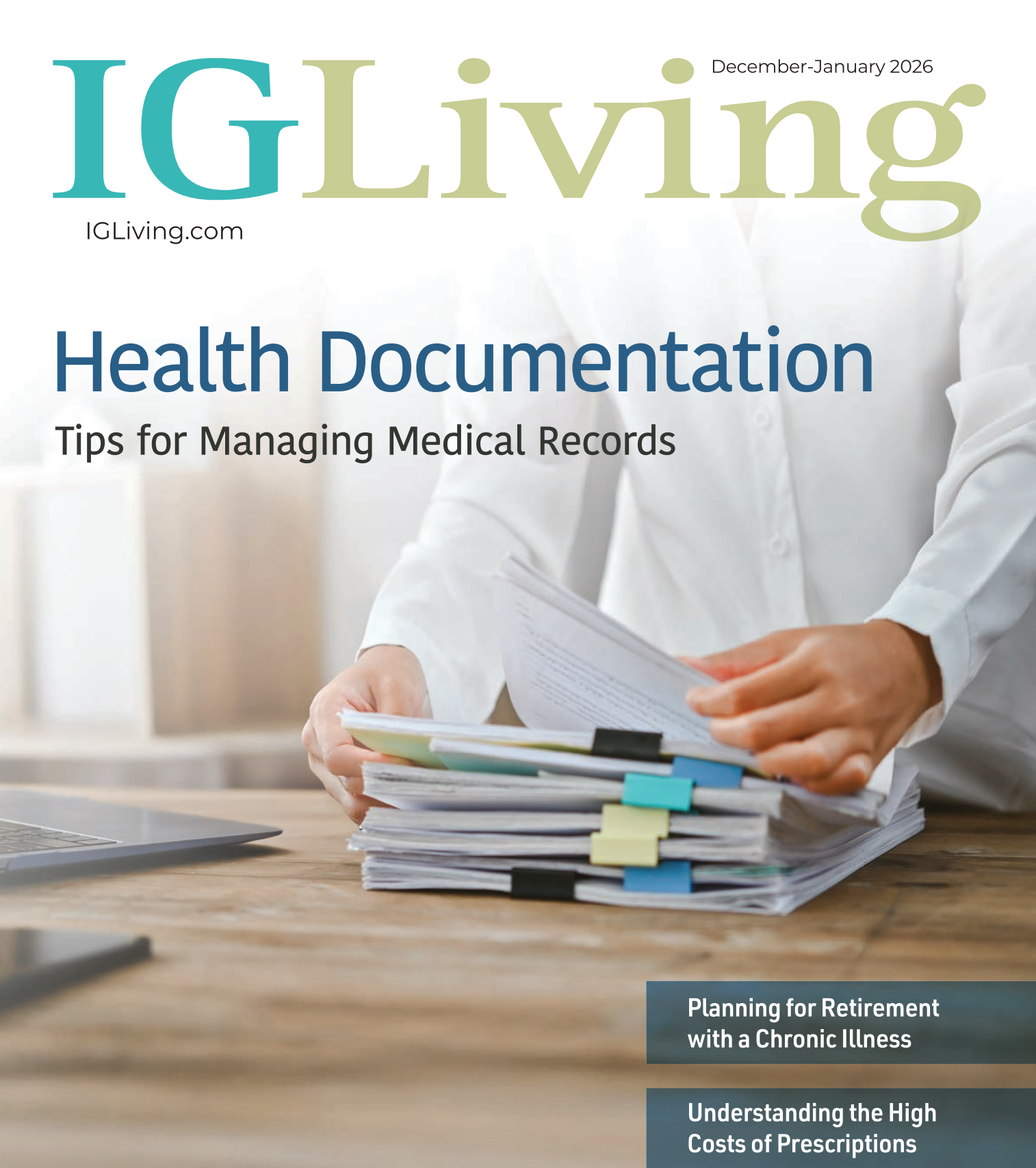
Health Documentation

Tips for Managing Medical Records



Planning for Retirement with a Chronic Illness

Understanding the High Costs of Prescriptions

Handy Kitchen Tools for Chronic Illness Patients

Diagnosing and Treating X-Linked Agammaglobulinemia

For patients with primary humoral immunodeficiency (PI)

IT'S WHAT'S INSIDE THAT COUNTS

ASCENIV™
IMMUNE GLOBULIN INTRAVENOUS (HUMAN) – slra 10% LIQUID

DESIGNED TO DELIVER™

Talk to your doctor about whether ASCENIV™ is right for you

asceniv.com

Important Safety Information for ASCENIV™

WARNING: RISK OF BLOOD CLOTS (THROMBOSIS), POOR KIDNEY FUNCTION, AND INABILITY TO FILTER WASTE FROM KIDNEYS. BLOOD CLOTS MAY OCCUR WITH INTRAVENOUS IMMUNE GLOBULIN PRODUCTS, INCLUDING ASCENIV.

Before taking ASCENIV, talk to your doctor if you:

- Are of advanced age
- Are unusually sedentary (long periods of sitting down or inactive)
- 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 do not have any risk factors.

Serious kidney problems and death can also happen in certain patients who receive such products.

If you are at high risk of thrombosis or kidney problems, your doctor should adjust the dose of ASCENIV and will monitor you for signs and symptoms of thrombosis and viscosity, as well as kidney function.

What is ASCENIV (immune globulin intravenous, human)?

ASCENIV (immune globulin intravenous, human) is a prescription medicine to help adults and adolescents (12 to 17 years old) with primary immunodeficiency fight and prevent infections.

ASCENIV is for intravenous administration only. ASCENIV is made from healthy human blood/plasma.

Who should not use ASCENIV?

ASCENIV should not be used if you had a severe allergic reaction to human immune globulin or if you have been told by a doctor that you are immunoglobulin A (IgA)-deficient and have developed antibodies to IgA and hypersensitivity after exposure to a previous plasma product.

What are possible warnings and precautions with taking ASCENIV?

Hypersensitivity. Severe allergic reactions may occur with immune globulin products, including ASCENIV. If you have a severe allergic reaction, stop the infusion immediately and get medical attention. ASCENIV contains IgA. If you have known antibodies to IgA, you may have a greater risk of developing potentially severe allergic reactions.

If you take ASCENIV or a similar immune globulin product, you could experience a serious and life-threatening blood clot (thromboembolism). This may include 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, numbness, or weakness on one side of the body. If you are at risk, your doctor may decide to adjust the dose of ASCENIV. Your doctor will monitor you for any signs or symptoms of blood clots or poor blood flow in your arteries.

Always tell your doctor immediately if your medical history is similar to what is described here, and especially if you experience any of these symptoms while taking ASCENIV.

Kidney problems or failure. Kidney problems, kidney failure, and death may occur with use of human immune globulin products, especially those containing sucrose (sugar). ASCENIV does not contain sucrose.

If you have kidney disease or diseases 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. If your doctor determines you to be at risk, they may start your dose of ASCENIV at a safe level.

People taking human immune globulin products, including ASCENIV, may experience hyperproteinemia (high levels of protein in the blood), hyponatremia (low levels of sodium in the blood), and hyperviscosity (poor blood flow). Your doctor may perform certain blood tests and monitor you to minimize any of the above risks.

Aseptic meningitis syndrome (AMS). Aseptic meningitis is a non-infectious inflammation of the membranes that cover the brain. It causes a severe headache, which may occur with human immune globulin treatment, including ASCENIV. AMS usually happens within a few hours to 2 days after treatment. AMS is more commonly associated with higher doses of treatment and/or after rapid infusion. Your doctor may perform a neurological exam, including spinal tap (sampling fluid which surrounds the spinal cord) to evaluate your condition and to rule out other causes of meningitis.

Hemolysis. Hemolysis refers to the destruction of red blood cells. Immune globulin products, including ASCENIV, may contain certain antibodies that can result in the rupturing of red blood cells. Your doctor should monitor you for signs and symptoms of hemolysis, which may include additional confirmation tests.

Taking intravenous human immune globulin products may cause a build up of fluid in the lungs (pulmonary edema) that is unrelated to heart problems. Your doctor should monitor you for lung-related side effects and may conduct appropriate tests that can detect the presence of certain white blood cells (anti-neutrophils) in the drug or your blood. If needed, your doctor may decide to use oxygen or other respiratory methods to help your breathing.

Transmissible infectious agents. Because ASCENIV 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. Your doctor will report to the manufacturer any cases of suspected infections spread by the product.

Interference with lab tests. Because ASCENIV contains a variety of antibodies that are infused into your body, blood tests to determine antibody levels may provide misleading interpretations. Be sure to always tell your doctor, nurse, or lab technician of any medicines you are taking and that you are using ASCENIV.

Interactions with medicines. ASCENIV can make vaccines (like measles, mumps, rubella, and chicken pox vaccines) less effective in your body. Before you get any vaccines, tell your healthcare provider that you take ASCENIV.

What are other possible side effects of ASCENIV?

In clinical studies of ASCENIV, some patients experienced the following:

- Headache
- Sinus inflammation (sinusitis)
- Diarrhea
- Intestinal lining inflammation caused by virus (gastroenteritis)
- Common cold (nasopharyngitis)
- Upper respiratory tract infection
- Bronchitis
- Nausea

These are not all the possible side effects of ASCENIV. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

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.

For additional safety information about ASCENIV, please see full Prescribing Information at www.asceniv.com

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About IG Living
IG Living magazine brings together patients, advocates and caregivers in the immune globulin (IG) community.

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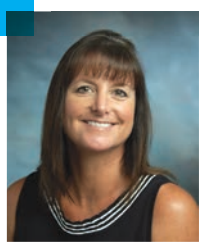
Managing Chronic Illness Records and Documents



HOW MANY of us can honestly say our medical and financial records and documents are in order to help us now and prepare us for the future? I know we'd all like to believe that, but the truth is while I do have most of my records, they consist of scattered files that would take even me a while to decipher. And, research shows that's the case for most Americans: A 2024 survey by Harmony Healthcare IT found 63 percent of Americans do not have their complete medical history and vaccination records dating back to birth, and a 2023 study from Northwestern Mutual found two-thirds of Americans say their financial planning needs improvement. While this could be problematic for everyone, it could present an even more pressing issue for individuals living with chronic illnesses. Those records and documents are the glue that hold your current and future well-being together. So, we hope the main articles in this issue will help you to get organized.

It's not enough to just have a medical record paper trail; these documents need to be organized and tracked to assist you when making provider changes, ensuring mistakes haven't occurred, etc. In our article "Managing Your Medical Records and Life Documents" (p.22), we outline which records and documents to keep such as diagnoses, procedures, lab tests and other services, insurance cards, advanced directives and more; why to keep them; and how to best organize and store them in both print and digital format. The key is to use whatever system works best for you.

When it comes to retirement, planning is especially important for those with chronic illnesses since so many factors come into play. We discuss these factors in our article "Retirement and Beyond: Planning for the Golden Years While Living with Chronic Illness" (p.26), including where and how to live, Medicare insurance options, where to receive medical care and which documents are crucial to have in place to ensure your medical needs and wishes are met. Equally important is sharing your preferences with loved ones and ensuring your legal documents are well organized and can be easily accessed by them to assist you.

While all of this planning is so important, no amount of planning can solve the high cost of medications. As patients living with chronic illnesses treated with immune globulin therapy, as well as many other medications, you may wonder why they are so costly. We make an effort to solve this puzzle in our article "The Pharmacy Prescription Price Puzzle" (p.30) by showing how pricing works, who controls costs and what policies are in place to help.

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

Ronale Tucker Rhodes, MS

IGLiving

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

A community service from FFF Enterprises, Inc.

Plasma – Instantly Accessible, Ultimately Lifesaving

At FFF Enterprises, we know your work is critical. That's why you can count on us for instant access to lifesaving plasma products your patients need – from immune globulin (IG), coagulation and albumin therapies to hyperimmune globulins and antithrombin treatments. Count on Us!

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  - IG Living, a magazine dedicated to the IG community

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Treating the Whole Person in Chronic Illness Care

By Abbie Cornett, MBA

LIVING WITH a chronic illness can feel as if a diagnosis has swallowed a patient's entire identity. Life becomes a never-ending cycle of doctor appointments, medication refills, lab work and missed events. The illness seems to take center stage, and too often, the rest of who that patient is seems to disappear. However, it's essential to remember that no patient is just a diagnosis, but rather so much more. That's why healthcare professionals must view the whole person to effectively treat patients, not just their illness. The World Health Organization defines health not only as the absence of disease but as "a state of complete physical, mental and social well-being."[1] And that definition matters. It reminds us that when healthcare treats only the body and ignores a patient's mind, emotions, relationships and purpose in life, it is only meeting half of that patient's needs.

Looking beyond symptoms. Of course, managing symptoms is essential for patients with chronic illnesses. But what about the rest of their daily lives? They may be told to eat well, but fatigue or financial strain can make cooking impossible. Or they may want to stay active, but don't know how to exercise safely with their condition. Supporting patients with nutrition counseling, physical therapy or adapted routines can transform care into something that genuinely improves day-to-day living.

The emotional weight. Chronic illness isn't only hard on the body; it can be hard on patients' mental health. Anxiety, depression and grief are common, yet too often overlooked. Patients may feel isolated, or even dismissed, when their symptoms aren't understood or validated. Creating space for mental health support is not an optional extra; it is an essential part of patient care. Access to therapy, peer support groups and stress management tools can help patients have a better quality of life.

The role of community. Often, a chronic illness diagnosis alters relationships. Friends and family may drift away. They may not know how to help, or worse, they may make patients feel judged, or worse yet, that they are faking it. As a result, patients may withdraw from social life due to fatigue, mobility issues or embarrassment. That isolation can be as damaging as the illness itself. Therefore, patients need to be encouraged to maintain existing connections and form new ones, whether through patient support groups, online networks or community support programs. Practical help matters too: Transportation services, food programs and housing resources can ease the daily strain of living with illness.

Work and identity. Many chronic illness patients face barriers at work. Because of their illness, many can no longer work full time or even part time. That loss of work identity can be devastating. It's important to remember that work is not the only way for people to find meaning. Volunteering, creative projects or flexible roles can help people feel valued and preserve dignity.

The spiritual dimension. For many people, spirituality provides strength when health falters. For some, this is tied to faith. For others, it's found in creativity, nature or personal reflection. These aspects of life are often easy to overlook in clinical care, but they are crucial. Asking about what gives patients hope or meaning and supporting those practices can provide comfort and connection in ways medicine alone cannot.

Putting the pieces together. Treating the whole person requires physicians, nurses, social workers, therapists, caregivers and patients to work as a team. The most effective care occurs when patients are actively involved in the process. Research shows that when care integrates physical, emotional and social needs, patients experience better outcomes and greater satisfaction.[2]

More than a diagnosis. People are not just their diagnosis! They are whole beings with histories, responsibilities and dreams that don't disappear when they become ill. While a chronic disease may change peoples' lives, it does not define who they are. When healthcare recognizes this and shifts its focus from just treating symptoms to treating the whole patient, it becomes more human.

References

1. World Health Organization. WHO Remains Firmly Committed to the Principles Set Out in the Preamble to the Constitution. Accessed at www.who.int/about/governance/constitution.
2. Kuipers, SJ, Cramm, JM, and Nieboer, AP. The Importance of Patient-Centered Care and Co-Creation of Care for Satisfaction with Care and Physical and Social Well-Being of Patients with Multi-Morbidity in the Primary Care Setting. *BMC Health Services Research*, 2019, Jan. 19;13:201. Accessed at bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3818-y.

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

What Advice Would You Give Someone Starting Their First IVIG or SCIG Infusion?

Hydrate well the day before, the day of and for a day or two after. It helps tremendously to minimize any possible side effects.

It's not as bad as you think it will be. Don't stress too much beforehand.

Drink lots of water the day before, the day of and the day after. Plus, you may have to slow down your infusion rate if you get side effects.

It could take several months for you to notice improvement, as it takes a long time for nerves to heal.

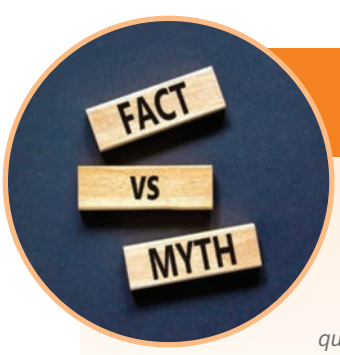
Everyone responds differently. You are your best advocate, so ask as many questions as you need to before, during and after.

How Long Did It Take for Your Immune Deficiency Diagnosis?

Several decades. I started getting infections as a baby and didn't get diagnosed until I was in my 30s. I can't help but wonder how much damage and heartache might have been avoided if I'd been diagnosed earlier.

62 years (now 65). Lifetime of illnesses and comorbidities. I was finally diagnosed when my oldest daughter was diagnosed [with] common variable immune deficiency at 25. Then I knew where she had got it from. I then went to an immunologist and insisted on being tested. Started subcutaneous immune globulin therapy a few months later.

I was 54 at diagnosis. By that time, I had lost most of my hearing and spent about half of my life sick and on steroids and antibiotics. It's a good thing I didn't follow one infectious disease doctor who told me my problem was my allergies to my dog and all I really needed to do was get rid of him.



What Myths Have You Heard About Subcutaneous Immune Globulin (SCIG) Therapy?

The one myth I wish would be addressed is the myth that it's the best choice always for every patient. There are those of us, like myself, who actively prefer intravenous IG and/or being in a clinic setting for various reasons. I feel like a lot of the time that gets shouted down by people who are zealous about promoting SCIG. Like you can't go into some patient groups and talk about IVIG without people questioning it and pushing SCIG. I feel like what we should be promoting is that every patient makes the best treatment decisions for their own needs, and that may look different for every individual.

For SCIG users, the needles are small, they don't hurt. Ummm…yes, yes they do [hurt] just like a tiny piece of wood called a splinter hurts you.

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.

Can an HSA Account Be Used with Medicare?

I have a health savings account (HSA) with a substantial balance, and I'm approaching the age to enroll in Medicare. Can you explain what types of expenses I can still use my HSA funds for after I go on Medicare? For example, can I use it to pay my Medicare premiums, deductibles or out-of-pocket costs for services that Medicare doesn't cover? Also, will I still be allowed to make new contributions to my HSA once I'm enrolled in Medicare, or do I need to stop contributing at a certain point? I'm trying to plan ahead and use the funds wisely for future medical expenses that may not be fully covered.

Abbie: As you get closer to Medicare enrollment, it's smart to think ahead about how to use your HSA effectively. You can use the money in your HSA to pay for many Medicare-related costs. These include your premiums for Medicare Part B (doctor visits and outpatient care), premiums for Medicare Part D (prescription drug coverage) and Medicare Advantage plans (Part C). You can also use it to pay for deductibles, co-payments and coinsurance.

However, HSA funds may not be used to pay premiums for Medigap policies. Beyond Medicare costs, your HSA can help with other qualified medical expenses that Medicare typically doesn't cover. These include dental care, vision exams and glasses, hearing tests and hearing aids.

If your Medicare premiums are taken out of your Social Security checks, you still have the option to reimburse yourself from your HSA later. Just be sure to save all your receipts and records for those expenses.

A few important things to remember:

- Once you enroll in any part of Medicare, you're no longer allowed to contribute to your HSA. You should stop contributions the month before your Medicare coverage starts.
- Any withdrawals you make from your HSA for qualified medical expenses are still tax-free, even after you go on Medicare.
- And finally, if you have a significant HSA balance, it's a good idea to speak with an estate planner to understand how those funds can be handled after your death.

Could Stomach Pain While Eating and Weight Loss Be Connected to Autoimmune Conditions?

I was diagnosed with undifferentiated connective tissue disease more than 15 years ago and later with Sjögren's syndrome. Recently, I've started having trouble eating. I get sick to my stomach and experience pain when I eat meats. I've been tested for meat sensitivity and other related conditions, but everything has come back negative. Could this be related to my autoimmune diseases? I'm losing weight and am worried since my doctors haven't been very helpful.

Abbie: According to Terry O. Harville, MD, PhD, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, some medications can contribute to nausea, stomach upset or pain with eating, so it's important to review what you're currently taking. In addition, Sjögren's syndrome itself can sometimes involve the gastrointestinal tract. One possible complication is gastroparesis, which occurs when the stomach doesn't empty properly and can cause pain, bloating and nausea. Therefore, a referral to a gastroenterologist would be helpful. He or she may recommend tests such as a stomach-emptying study or an endoscopy to look for underlying issues. If gastroparesis or another motility disorder is found, there are medications that can improve gastric motility and ease your symptoms.

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

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Befriend Your Mind

By Mairead McConnell, PhD

SYMPTOMS OF anxiety and depression are common, affecting approximately 20 percent of all adults in the United States. For those living with chronic illness, these rates are even higher, and the impact can range from bothersome to debilitating. When your mental health is struggling, it can feel like your mind is working against you. Maybe you've even heard or thought that you are "your own worst enemy." These feelings are valid and common. However, battling against your own mind often makes things harder. Instead, consider a new approach: treating your mind as an ally. You and your mind are on the same team.

Not the Enemy

Everything your mind does — from generating creative ideas to scanning for danger — is ultimately an attempt to protect you. Our brains evolved to help us survive. Their intentions are good. But constantly scanning for threats doesn't help us remain calm or at ease. In fact, this protective instinct can sometimes contribute to anxiety and make life more difficult. Still, your mind is not your enemy. Think of it more like an overprotective parent or a scared child — wanting so badly to help but not always knowing how.

Thank You, Mind!

One simple way to befriend your mind is to thank it. When your mind does something helpful, acknowledge it with genuine gratitude: "Thank you for helping me navigate that situation!" When your mind gets stuck in a spiral of worry or negativity, try a lighter, more humorous tone: "Thanks, mind!" Not everything your mind tells you is true, and importantly, not every thought deserves your full attention. You get to decide which thoughts you hold on to and which ones you let go. Some thoughts are best met with: "Thanks, but no thanks!"

Not everything your mind tells you is true, and importantly, not every thought deserves your full attention.

Clouds in the Sky

At times, your mind might feel like an overwhelming or even hostile place. Shifting this experience will take time, but you can begin to build a sense of safety within yourself. Start small. Try this simple exercise from acceptance and commitment therapy called "Clouds in the Sky":

1) Sit with your eyes closed or with a soft downward gaze.

2) Take three slow breaths in through the nose, out through the mouth.

3) Imagine you are lying in a grassy meadow on a peaceful day, looking up at a wide-open sky. The sky is your mind — vast and blue.

4) In the sky, fluffy white clouds begin to drift by. These clouds are your thoughts.

5) As you lie in the meadow, simply observe these thoughts as they float past. Some clouds may carry words, images or memories. You don't need to interact with them, change them or chase them; just notice them and let them drift on.

6) If emotions arise, let those drift by too. When you get caught up in a thought (which is completely normal), gently return to the meadow and continue observing.

You and Your Mind

For better or worse, your mind is always with you. It has grown and developed alongside you, but it is not you. You can observe it, appreciate it and even laugh at it sometimes. Your mind is doing its best to help. Let it be your friend and supporter. IG

MAIREAD MCCONNELL, PhD, is a clinical psychologist and assistant professor at Banner University Medical Center in Tucson, Ariz. She specializes in health psychology and is passionate about helping patients live well while navigating the challenges of chronic illness.

Important Safety Information

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.

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

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.

Hizentra®
Immune Globulin Subcutaneous (Human) 20% Liquid

Get the protection of Ig without the IV

- **NO SERIOUS BACTERIAL INFECTIONS REQUIRING HOSPITALIZATION***
- **CONTINUOUS PROTECTION**
- **NO SERIOUS SIDE EFFECTS†**

IVIg may leave you feeling sick before and after infusions. But Hizentra gives you continuous Ig protection plus the ability to self-infuse where and when you choose after speaking to your doctor. With no serious bacterial infections,* you get more freedom and confidence in everyday moments. It's time to ask your doctor if Hizentra is right for you.

LIVE IN ***STRENGTH***
WITH HIZENTRA

Scan for more reasons to switch

*In a 12-month study, Hizentra delivered low rates of infection with no serious bacterial infections that could potentially require hospitalization, like bacterial pneumonia, bacteremia/septicemia, osteomyelitis/septic arthritis, bacterial meningitis, and visceral abscess.

†In the 12-month study of people taking Hizentra to treat PI, there were no serious side effects related to treatment. Two subjects withdrew from the 12-month study due to nonserious side effects.

Ig, immunoglobulin; IVIg, intravenous immunoglobulin.

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.

Immediately report to your physician any of the following symptoms, which could be signs of serious adverse reactions to Hizentra:

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

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

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

CSL Behring

Hizentra®
Immune Globulin Subcutaneous (Human) 20% Liquid

Important Safety Information (continued)

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 accompanying full prescribing information for Hizentra, including boxed warning and the patient product information.

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.

HIZENTRA®, Immune Globulin Subcutaneous (Human), 20% Liquid Initial US Approval: 2010

BRIEF SUMMARY OF PRESCRIBING INFORMATION

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

What is HIZENTRA?

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

Who should NOT take HIZENTRA?

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

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

What are possible side effects of HIZENTRA?

The most common side effects with HIZENTRA are:

- Redness, swelling, itching, and/or bruising at the infusion site
- Headache/migraine
- Nausea and/or vomiting
- Pain (including pain in the chest, back, joints, arms, legs)
- Fatigue
- Diarrhea
- Stomach ache/bloating
- Cough, cold or flu symptoms
- Rash (including hives)
- Itching
- Fever and/or chills
- Shortness of breath
- Dizziness
- Fall
- Runny or stuffy nose

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

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

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

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

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

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

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

Based on April 2023 version.

CSL Behring

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SARS-CoV-2 and COVID-19: Vaccination!

By Terry O. Harville, MD, PhD

THE SUDDEN appearance of SARS-CoV-2 at the end of 2019 and beginning of 2020 caught essentially everyone off guard, especially in terms of how to deal with this novel zoonotic coronavirus. There were no antiviral agents available, and as with any infection, prevention via vaccination was the most judicious approach — thus, the "immediate" rush to develop applicable vaccines.

Traditionally, vaccines have been made by a few general methods. One method is to grow the microorganism and kill it (bacteria) or inactivate it (virus), extract the protein components and place them into a buffer medium for eventual injection into people. The buffer medium may contain what is called an "adjuvant," which is a compound that can help activate the immune system and thus make the vaccine more potent. The second common method is to grow the virus in such a manner that it loses its virulence in humans but can still grow to some extent in them. This approach was used with the Sabin polio vaccine to cause localized immunity in the gastrointestinal tract where immunity was needed to prevent polio infection. These are the so-called "live-viral vaccines," which can pose problems for people with immunodeficiencies or those who are otherwise immunocompromised.

Another method, the originally known vaccination process discovered by Edward Jenner, MD, involves using a similar organism that is nonvirulent in people to induce an immune response against the virulent human form. This was called "variolation" (using a needle to scratch the lesion of the infected animal

or person and then scratching the skin of the noninfected person to induce mild infection growth and an immune response) in which cowpox virus could induce immunity in people against smallpox. This, too, is a risk for people with immunodeficiency or those who are otherwise immunocompromised.

Thus, to develop a traditional vaccine that is not a risk for these populations, the virus first needed to be identified (found and labeled as SARS-CoV-2), then grown in some culture process (to identify which cells the virus can reproduce to great levels for eventual isolation of the viral proteins for the vaccine), tested for safety and distributed for use.

Initially, this seemed almost insurmountable. Yet, thankfully, serendipitous advancements had been made during the prior 20 years or so; otherwise, the pandemic could have been much, much worse in terms of lives lost. In 2002, SARS (severe acute respiratory syndrome due to the coronavirus now known as SARS-CoV-1), the original modern zoonotic coronavirus with human pandemic potential, arose in Southeast Asia, but quarantine procedures limited the spread and prevented a worldwide pandemic. In 2012, MERS (Middle Eastern respiratory syndrome) arose, another unique zoonotic coronavirus (MERS-CoV) thought to spread from camels into humans. Fortunately, the relative isolation of Saudi Arabia helped to limit its spread. Due to the realistic concerns, we were fortunate at that time that a worldwide pandemic did not occur, and we knew we needed to be ready if these reemerged with pandemic potential.

So, work had begun to develop vaccines for SARS-CoV-1 and MERS-CoV using the traditional approach of creating a "protein-extract" vaccine, by growing the viruses in suitable cell cultures. More importantly, though, especially for the control of a pandemic, a new concept for vaccine development was utilized. Work had been performed with packaging mRNA into lipid vesicles to deliver the mRNA into cells, with the expectation that the mRNA would be translated into proteins to carry out a specific function needed in that cell. For example, this approach was being developed and tested as a way to control cancer cells.

Next time, we will go into more detail about the vaccines used to prevent or lessen the severity of SARS-CoV-2.

TERRY O. HARVILLE, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences and a consultant for immunodeficiencies, autoimmunities and transplantation.

Understanding RSV

By Michelle Greer, RN, IgCN

RESPIRATORY syncytial virus (RSV) is a virus that can cause respiratory infection and illness in people of any age. However, it is one of the most common causes of respiratory illness in infants and children around the world. RSV is specific to the respiratory tract, affecting the nose and the lungs. It is highly contagious among young children: It spreads through direct contact with droplets from an infected individual's cough or sneeze, or through contact with surfaces contaminated by these droplets.[1]

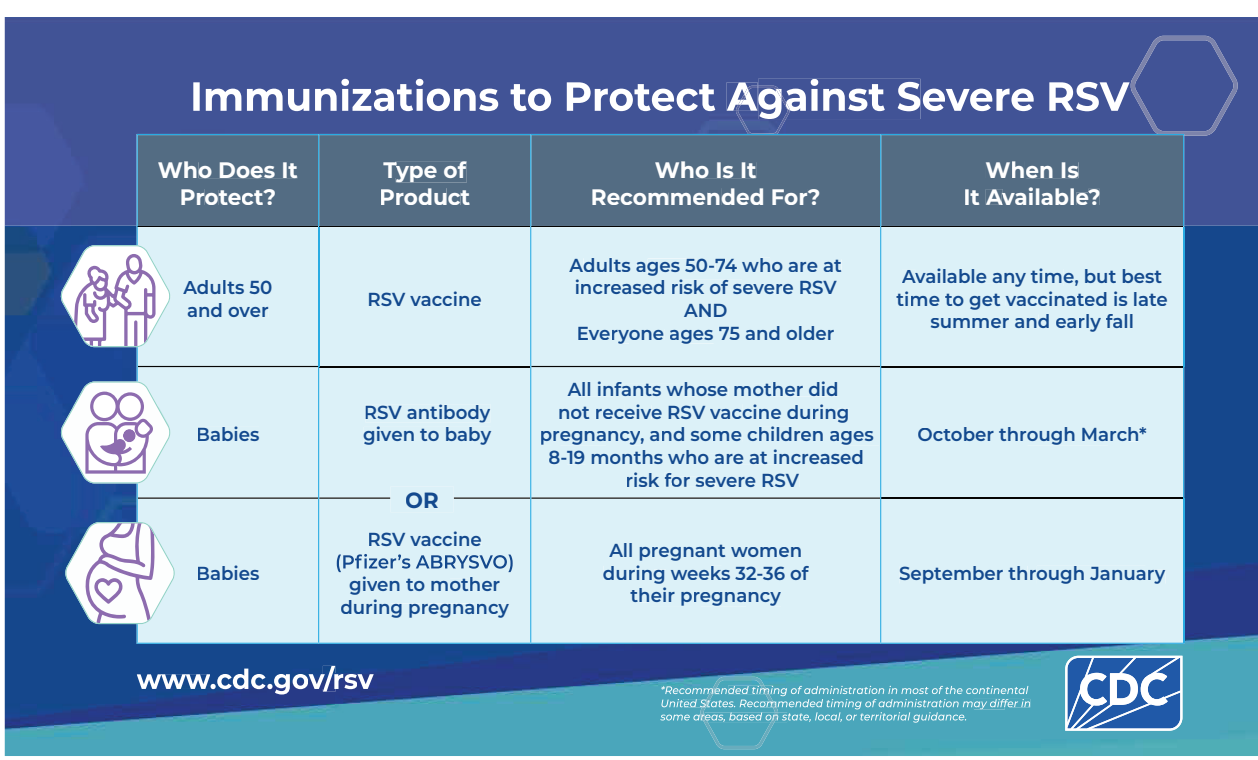
RSV Incidence

RSV season typically begins in late fall and continues into early or mid-spring. Each year, RSV causes an estimated 3.6 million RSV-associated hospitalizations and approximately 100,000 RSV-attributable deaths in children under 5 years of age worldwide.[2] While the incidence of RSV was decreased during the COVID-19 pandemic, it has increased since. One study in a New York City hospital showed a lower number of RSV cases and lower rate of hospitalization for RSV during the first season of the COVID-19 pandemic followed by a higher number of RSV cases in the second season.[3] Globally, studies from the United States, Australia, Japan and England all demonstrated a decline in RSV illness during the first season of the pandemic followed by a robust rebound in incidence during the second season.[3] Another study suggests a gradual return to the usual prepandemic pattern, although further updated studies are needed to confirm this trend. This study also suggests that regular exposure to RSV among older children plays a significant role in preserving immunity at a level sufficient to prevent severe outcomes.[4]

By 2 years of age, almost all children have had at least one RSV infection, and if infection recurs, it should be with lesser severity. If RSV recurs in older age with underlying comorbidities, symptoms could be more severe. This is typical of most viruses; severity depends on the host and other environmental factors.

RSV Symptoms

Symptoms are typically mild and similar to a common cold: runny nose, sore throat, coughing, sneezing and low-grade fever. However, RSV can cause severe infection in some people,



including babies 12 months and younger (infants), especially premature infants; older adults; people with heart and lung disease; or anyone with a weak immune system (immunocompromised).[5]

Complications occur when the infection moves from an upper respiratory infection to the lower lungs, at which point bronchiolitis or pneumonia can result. Cough may become more severe, with wheezing and difficulty breathing. Infants may not feed well. Lethargy and irritability may occur as well. It can also exacerbate heart and lung issues in people with those underlying conditions.

RSV Treatment

There is no specific treatment for RSV. Recovery time is one to two weeks and involves rest and other self-care measures that are typically used to recover from the common cold. But if symptoms progress, urgently seeking medical attention is warranted. In severe cases, hospitalization may be needed as well.

RSV Prevention

There are some vaccine and immunization options available, including:

- AREXVY is a vaccine indicated for active immunization for the prevention of lower respiratory tract disease (LRTD) caused by RSV in individuals 60 years of age and older, as well as individuals 50 through 59 years of age who are at increased risk for LRTD caused by RSV.[6]
- BEYFORTUS is an RSV F protein-directed fusion inhibitor indicated for the prevention of RSV LRTD in neonates and infants born during or entering their first RSV season and children up to 24 months of age who remain vulnerable to severe RSV disease through their second RSV season.[7]
- ABRYSVO is a vaccine indicated for active immunization for the prevention of LRTD caused by RSV in individuals 60 years of age and older, active immunization of pregnant women at 32 through 36 weeks gestational age for the prevention of LRTD and severe LRTD caused by RSV in infants from birth through 6 months of age, and active immunization for the prevention of LRTD caused by RSV in individuals 18 through 59 years of age who are at increased risk for LRTD caused by RSV.[8]

In most of the continental United States, pregnant women should receive an RSV vaccine from September (one to two months before the anticipated start of RSV season) through January (two to three months before the anticipated end of the RSV season) so that their babies are protected against severe RSV disease at birth.[9]

Take Precautions, But Seek Medical Help if Necessary

Some patients with RSV may experience mild symptoms similar to a common cold, while other patients may develop severe illness. Infants younger than 6 months and older adults with certain risk factors are especially vulnerable to severe disease, so precautions should be taken. Wash your hands, limit exposure to germs, consistently clean high-touch surfaces and consider vaccination.

If you or a loved one gets sick with RSV, implementing comfort measures may be sufficient. Using a cool-mist humidifier and nasal saline spray, drinking plenty of fluids or taking over-the-counter acetaminophen or ibuprofen may ease mild symptoms. However, more severe symptoms require medical attention. See the doctor if your loved one is younger than 12 months old and has a fever higher than 104 degrees Fahrenheit, ear drainage or tugging at ears, difficulty breathing or bad coughing fits, wheezing or noisy breathing or symptoms that do not improve (or worsen) after a week. If you are over age 65 and have a compromised immune system or heart or lung condition, call your doctor to discuss your condition.[10]

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MICHELLE GREER, RN, IgCN, is senior vice president of sales at Nufactor, a specialty infusion company.

MEDICINES

Kedrion's QIVIGY (10% IVIG) Approved By FDA

Kedrion Biopharma has received U.S. Food and Drug Administration (FDA) approval for QIVIGY, a new 10% intravenous immune globulin (IVIG), indicated for treatment of adults with primary immunodeficiency (PI). Approval is based on clinical study outcomes that showed patients on this treatment can expect fewer infections and less time away from school and work.

The product will be launched in the U.S. first, with plans for global expansion in Europe and other markets upon approval. The new therapy is expected to be available in the U.S. in early 2026.

"Seeing QIVIGY receive FDA approval is a deeply meaningful moment for all of us at Kedrion," said Ugo Di Francesco, Kedrion's chief executive officer. "It reflects not only [on] our scientific and operational capabilities, but also the heart and purpose that drive our mission to serve patients. Today, we celebrate two success stories: one in the delivery of a product that helps improve patient care and another that defines us as an organization, demonstrating our ability to deliver while also illuminating the path ahead." IG

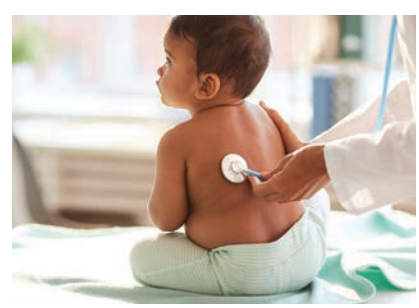
Kedrion Biopharma Receives FDA Approval for QIVIGY® and Confirms Its Plan to Increase Investments in the US Throughout Its Global Operations. Kedrion Biopharma press release, Sept. 29, 2025. Accessed at www.kedrion.com/kedrion-biopharma-receives-fda-approval-for-qivigy-and-confirms-its-plan-to-increase-investments-in-the-us-throughout-its-global-operations.

RESEARCH

Study Finds Children with PI Are at High Risk for Developing Secondary Malignancies

In a study that aimed to evaluate the clinical features and types of primary immunodeficiency (PI), associated secondary malignancies, treatment modalities and outcomes among pediatric patients with PI treated at a tertiary care center in Saudi Arabia, researchers found children with PI are at high risk for developing early-onset, aggressive malignancies, especially hematologic cancers.

The retrospective observational cohort study included 28 pediatric patients diagnosed with both PI and malignancy at King Fahad Medical City, Riyadh, between January 2009 and January 2023. Clinical, demographic and treatment-related data were collected and analyzed using descriptive statistics and Kaplan-Meier survival analysis. Among the 1,793 pediatric oncology patients reviewed, 28 (1.56 percent) were diagnosed with both PI and a secondary malignancy. Most patients were male (64.3 percent) and Saudi nationals (82.1 percent). Hematologic malignancies were predominant (85.7 percent), with secondary hemophagocytic lymphohistiocytosis (42.9 percent) and diffuse large B-cell lymphoma (21.4 percent) being the most common. Griscelli syndrome (32.1 percent) and ataxia-telangiectasia (17.9 percent) were the most frequently observed PI. Chemotherapy was administered to 96.4 percent of patients, with dose adjustments required in 25.9 percent. Febrile neutropenia was reported in 70.4 percent, and infections were documented in 75 percent of cases. Bone marrow transplantation was performed in 39.3 percent of patients. Progression-free survival was 92.2 percent, and overall survival was 64.3 percent, with sepsis accounting for 80 percent of deaths.



According to the researchers, despite significant treatment-related complications and infection susceptibility, curative approaches such as chemotherapy and transplantation are feasible. Early identification, individualized treatment and aggressive infection control are crucial to improving survival outcomes in this high-risk population. IG

Alnakhli, A, Almanjomi, F, Alrasheedi, H, et al. Characteristics of Secondary Malignancy Among Children With Primary Immunodeficiency Disorders in Saudi Arabia. Cureus, Sept. 28, 2025. Accessed at hwww.cureus.com/articles/407264-characteristics-of-secondary-malignancy-among-children-with-primary-immunodeficiency-disorders-in-saudi-arabia#!.

MEDICINES

FDA Approves Gammagard Liquid ERC to Treat PI, Plans to Discontinue Gammagard S/D in December 2027

The U.S. Food and Drug Administration (FDA) has approved GAMMAGARD LIQUID ERC [immune globulin infusion (human)] with less than or equal to 2 µg/mL IgA in a 10% solution, the only ready-to-use liquid immune globulin (IG) therapy with low immunoglobulin A (IgA) content, as replacement therapy for individuals 2 years of age and older with primary immunodeficiency (PI). As a ready-to-use liquid, GAMMAGARD LIQUID ERC may help ease the administration burden for patients and their healthcare providers by eliminating the need for reconstitution and can be administered intravenously or subcutaneously. Takeda anticipates commercialization of GAMMAGARD LIQUID ERC will begin in the U.S. in 2026.

"The approval of GAMMAGARD LIQUID ERC reinforces our commitment to supporting individualized treatment approaches for people with [PI], including a therapeutic option that has the lowest IgA content of any ready-to-use liquid [immune globulin] therapy, and can be administered intravenously or subcutaneously," said Kristina Allikmets, senior vice president and head of research and development for Takeda's Plasma-Derived Therapies Business Unit. "GAMMAGARD LIQUID ERC uses the same state-of-the-art manufacturing process as our other ready-to-use liquid [immune globulin] formulations and is aligned with our forward-looking strategy to prioritize reliable supply while offering a broad range of immunoglobulin therapies to address varied patient needs."

In parallel to this approval, and after thorough analysis, Takeda has decided to discontinue GAMMAGARD S/D [immune globulin intravenous (human)] IgA less than 1 µg/mL in a 5% solution, the company's first-generation low IgA product. As the only lyophilized (freeze-dried) preparation in Takeda's IG portfolio, GAMMAGARD S/D uses a different, older manufacturing process. For GAMMAGARD S/D, this process is no longer able to reliably meet the future needs of the patient community. Therefore, Takeda has informed FDA and other health authorities that manufacturing of GAMMAGARD S/D will be discontinued at the end of December 2027. Beyond that date, Takeda intends to maintain GAMMAGARD S/D inventory until it is depleted or expired.

"We understand the impact that this news may have on patients who currently rely on GAMMAGARD S/D for their treatment," said Allikmets. "We are communicating this information now to allow time for patients to work closely with their healthcare teams to develop alternative treatment plans." IG

Takeda Announces U.S. FDA Approval of GAMMAGARD LIQUID ERC, the Only Ready-to-Use Liquid Immunoglobulin Therapy with Low Immunoglobulin A (IgA) Content. Takeda press release, June 30, 2025. Accessed at www.takeda.com/newsroom/newsreleases/2025/gammagard-immunoglobulin.

RESEARCH

Risk of Mental Health Disorders Nearly Twice as High in Patients with Autoimmune Disease

Patients with autoimmune conditions and chronic inflammation may be at twice the risk for mental health disorders such as depression, bipolar disorder and anxiety versus the general population, according to data published in *BMJ Mental Health*. "We have more than 20 years of research suggesting that there may be a link between inflammation and mental health issues," said Arish Mudra Rakshasa-Loots, PhD, of the division of psychiatry and center for clinical brain sciences at The University of Edinburgh. According to Dr. Mudra Rakshasa-Loots, some immunopsychiatry clinics in Europe have begun early-stage testing of anti-inflammatory interventions for patients with mental health disorders.

To assess the link between autoimmune disease and affective disorders, Dr. Mudra Rakshasa-Loots and colleagues examined data from the Our Future Health research cohort, which included 1,563,155 participants (mean age 53.2 years) in the United Kingdom. Of those patients, 37,808 had lifetime diagnoses of one of six autoimmune conditions: rheumatoid arthritis, Graves' disease, inflammatory bowel disease, lupus, multiple sclerosis and psoriasis.

According to the researchers, patients with an autoimmune condition demonstrated significantly higher rates of depression (28.8 percent versus 17.9 percent), bipolar disorder (28.4 percent versus 17.8 percent) and anxiety (29.3 percent versus 18 percent) compared with healthy participants. The researchers additionally found risk for mental health issues in this patient group remained higher even after controlling for variables such as income, history of chronic pain and history of social isolation.

"Women were at higher risk for mental health disorders, even when compared with men with the same autoimmune conditions, and the risk was nearly identical across all of the mental health disorders we studied," Dr. Mudra Rakshasa-Loots said. He recommends regular mental health screenings and tailored interventions be integrated into care plans for patients with autoimmune conditions. "Future research should aim to identify the mechanisms behind this high prevalence of mental health issues, and in particular explore the biological or social reasons behind the higher prevalence among women," he added. IG

Wursta, MR. Anxiety, Bipolar Disorder Risks Nearly Twice as High in Patients with Autoimmune Disease. Healio, Sept. 15, 2025. Accessed at www.healio.com/news/rheumatology/20250912/anxiety-bipolar-disorder-risks-nearly-twice-as-high-in-patients-with-autoimmune-disease.

RESEARCH

Study Finds Veterans with Lupus and RA Have Higher Pregnancy Risks

A new study in *ACR Open Rheumatology* reveals that female veterans with systemic lupus erythematosus (SLE) or rheumatoid arthritis (RA) have higher risks of pregnancy loss and severe maternal morbidity compared to other veterans.

Researchers analyzed health records from the Department of Veterans Affairs (VA) from 2009 to 2019 and identified 29,713 pregnancies, including 113 in women with SLE and 92 with RA. Among these, 36 percent of SLE pregnancies and 30 percent of RA pregnancies ended in nonlive births (stillbirth, ectopic pregnancy or miscarriage), compared to 25 percent in other veterans. Rates of life-threatening maternal complications, such as renal failure, sepsis and need for transfusion, were also elevated.

Comorbid conditions were also common: Nearly one in five veterans with SLE had end-stage kidney disease, and more than one-third had pulmonary hypertension, which both contributed to poor pregnancy outcomes. Notably, half of the women with lupus were Black.

The authors conclude that VA maternity care models must better integrate rheumatology expertise to support those with autoimmune conditions. They also stress the need for tailored strategies that address overlapping medical, mental health and social risks. IG

Veterans with Lupus and RA Have Higher Pregnancy Risks. Global Autoimmune Institute, Sept. 3, 2025. Accessed at www.autoimmuneinstitute.org/research_updates/veterans-with-lupus-and-ra-have-higher-pregnancy-risks.

RESEARCH

GLP-1s May Improve RA Symptoms

A recent study published in *ACR Open Rheumatology* showed that patients with rheumatoid arthritis (RA) who are also overweight or obese taking a GLP-1 saw reductions in their RA symptoms, pain, body weight, cholesterol and blood sugar levels, compared with the control group.

A team of researchers examined the medical records of obese and overweight RA patients prescribed GLP-1 agonist drugs and identified 229 patients with a BMI of at least 27. Patients in the treatment cohort were given either subcutaneous semaglutide (84 percent), oral semaglutide (eight percent) or subcutaneous tirzepatide (eight percent). Of the 173 obese or overweight patients who took their prescribed GLP-1s, 32 percent saw improvement in their RA symptoms over a year, compared with 17 percent of the 42 patients who were prescribed a GLP-1 but did not take it. Patients were seen at three-month intervals for up to one year.

Although this difference is not considered statistically significant (P=0.16), decreases were seen in multiple areas. For example, disease activity was categorized on a scale of 0 to 3 (remission to severe), and for those using GLP-1 agonists, group averages changed by -0.03 points. On the standard 0 to 10 self-reported pain scale, pain decreased by an average of 0.6 points, compared with an increase of 1.3 points for those in the control group. Patients taking GLP-1s also lost an average of 9.7 pounds from baseline, as well as saw drops in triglyceride, low-density lipoprotein and cholesterol levels.

More than 30 percent of RA patients in North America are obese, due to the nature of the diseases exacerbating each other. The overproduction of inflammatory cytokines and adipocytokines caused by RA puts these individuals in a chronic inflammatory state. The leading cause of death in obese RA patients is cardiovascular disease. The cardiovascular benefits of GLP-1 use in RA patients are well established, while the drug's possible anti-inflammatory benefits continue to be researched.

According to the researchers, existing research has shown that GLP-1RA may down-regulate the secretion of multiple proinflammatory cytokines, which suggests a possible mechanism by which they may impact RA disease activity. The team also found that GLP-1RAs have been shown to modulate arthritis pain through multiple possible mechanisms.

"Our study is among the first to assess the effects of GLP-1RAs on patients with RA, and our findings suggest that they may beneficially impact RA care in several important ways," the researchers wrote. "Further study in the form of prospective trials is needed to better characterize their benefits and risks in this patient population." IG

Lutton, L. GLP-1s Improve Rheumatoid Arthritis Symptoms, Study Suggests. Managed Healthcare Executive, Sept. 15, 2025. Accessed at www.managedhealthcareexecutive.com/view/glp-1s-improve-rheumatoid-arthritis-symptoms-study-suggests.

RESEARCH

Antibiotics in Pregnancy and Infancy Not Found to Be Linked to Autoimmune Risk

A nationwide Korean cohort study published in *PLOS Medicine* followed more than five million children to test whether antibiotics given during pregnancy or in the first six months of life raise the risk of autoimmune disease. The autoimmune diseases of interest were type 1 diabetes, juvenile idiopathic arthritis, Crohn's disease, ulcerative colitis, systemic lupus erythematosus and Hashimoto's thyroiditis.

The researchers found no overall association between antibiotic exposure during pregnancy or early infancy and the development of autoimmune disease. To reduce bias from infections and family factors, they applied inverse probability weighting and sibling-matched analyses, both of which "showed null association between antibiotic exposure and autoimmune diseases in children." Some subgroups showed modest autoimmune risk increases, including Crohn's disease and autoimmune thyroiditis.

Overall, the findings are reassuring for families and clinicians: When antibiotics are prescribed for real infections in pregnancy or infancy, they

do not appear to raise children's long-term risk of autoimmune disease. IG

Global Autoimmune Institute. Antibiotics in Pregnancy and Infancy Not Linked to Autoimmune Risk. Global Autoimmune Institute, Aug. 26, 2025. Accessed at www.autoimmuneinstitute.org/research_updates/antibiotics-in-pregnancy-and-infancy-not-linked-to-autoimmune-risk.

FDA-approved for adult and pediatric patients aged 2 years and older with primary immunodeficiency (PI)

cutaquig®
Immune Globulin Subcutaneous (Human)-hipp, 16.5% solution

Count the reasons

to ask your care team about cutaquig

1 hour or less to **complete infusion***

2 or fewer **infusion sites**†‡

3 **flexible dosing** schedule options§

Not an actual patient.

*The estimated infusion duration for a 13 g (78 mL) weekly dose is approximately 45 minutes in an adult patient using 2 infusion sites, if tolerated, not including setup time.
†Depending on your dose and dosing schedule selected.
‡Most infusions only need 2 or fewer infusion sites.
§Every-other-week, weekly, or frequent dosing (2-7 times a week).

INDICATIONS AND USAGE

CUTAQUIG (Immune Globulin Subcutaneous [Human] - hipp) is a 16.5% immune globulin solution for subcutaneous infusion indicated for treatment of primary humoral immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

There are many forms of PI. Certain types of PI are associated with low immunoglobulin G (IgG), which are proteins that help fight infection.

CUTAQUIG is a liquid medicine for infusion that contains immunoglobulin G (IgG), which are proteins that help fight infection. It is made from human plasma that is donated by healthy people and contains antibodies that replace the missing antibodies in patients with PI.

CUTAQUIG is given under the skin (subcutaneous). Most of the time, infusions under the skin are given at home by self-infusion or by a caregiver. Only use CUTAQUIG by yourself after you have been instructed on use by a healthcare provider (HCP).

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS

See full Prescribing Information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin products, including CUTAQUIG. 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.**
- **For patients at risk of thrombosis, administer CUTAQUIG 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 of hyperviscosity.**

What is the most important information I need to know about CUTAQUIG?

CUTAQUIG can cause the following serious reactions:

- Severe allergic reactions causing difficulty in breathing or skin rashes
- Blood clots in the heart, brain, lungs, or elsewhere in the body
- Severe headache, drowsiness, fever, painful eye movements, or nausea and vomiting
- Decreased kidney function or kidney failure
- Dark colored urine, swelling, fatigue, or difficulty breathing

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

Scan to visit **CutaquigInfo.com** to learn more.

What should I know while taking CUTAQUIG?

- CUTAQUIG can make vaccines (like measles/mumps/rubella or chickenpox vaccines) not work as well for you. Before you get any vaccines, tell your HCP that you take CUTAQUIG
- Tell your HCP if you are pregnant, or plan to become pregnant, or if you are nursing

CUTAQUIG can cause serious side effects. If any of the following problems occur after starting CUTAQUIG, contact your HCP or call emergency services. If any of the following problems occur during CUTAQUIG infusion, stop the infusion immediately and contact your HCP or call emergency services:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting, or dizziness. These could be signs of a serious allergic reaction
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem
- Chest pain or trouble breathing, or blue lips or extremities. These could be signs of a serious heart or lung problem
- Fever over 100°F. This could be a sign of an infection

Ask your HCP whether you should have rescue medications available, such as antihistamines or epinephrine.

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

The most common side effects of CUTAQUIG are:

- Infusion site reactions (including but not limited to redness, swelling, itching, fluid in tissue, pain, mass, bruising)
- Headache
- Elevated body temperature

One or more of the following possible side effects may occur at the site of infusion; these may go away within a few hours and are less likely after the first few infusions:

- Mild or moderate pain
- Redness
- Itching

These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

CUTAQUIG® is a registered trademark of Octapharma AG.

Please see brief summary of Full Prescribing Information on following page and Full Prescribing Information, including complete BOXED WARNING and Patient Information and Instructions for Use, at CutaquigInfo.com.

Pfizer | octapharma | Manufactured by Octapharma Pharmazeutika Produktionsges m.b.H.
Distributed by Pfizer Labs, Division of Pfizer Inc.

PP-CQG-USA-0561

March 2023

cutaquig®
Immune Globulin Subcutaneous (Human)-hipp,16.5% solution

CONSUMER BRIEF SUMMARY

(CUTAQUIG: *cute-ah-quig*)

This brief summary highlights the most important information about CUTAQUIG. Please read it carefully before using CUTAQUIG and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment. If you have any questions after reading this, ask your healthcare provider. For more information, go to www.CutaquigInfo.com.

What is CUTAQUIG?

CUTAQUIG is a ready-to-use liquid solution of immunoglobulin G (IgG), also called antibodies, which protects the body against infection. CUTAQUIG is used to treat adult patients and pediatric patients 2 years of age and older with primary humoral immunodeficiency (PI).

There are many forms of PI. The most common types of PI result in an inability to make a very important type of protein called antibodies, which help the body fight off infections from bacteria or viruses. Regular administration of CUTAQUIG has been demonstrated to help your body to fight bacteria and viruses that cause infections. CUTAQUIG is made from human plasma that is donated by healthy people. CUTAQUIG contains antibodies collected from these healthy people; these antibodies replace the missing antibodies in patients with PI.

WARNING: THROMBOSIS

See full Prescribing Information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin products, including CUTAQUIG. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling central vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **For patients at risk of thrombosis, administer CUTAQUIG 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 of hyperviscosity.**

Who should NOT use CUTAQUIG?

Do not use CUTAQUIG if you have ever had a severe allergic reaction to immune globulin or other blood products.

Tell your healthcare provider if you:

- Ever had any severe reaction to other immune globulin medicines
- Were told that you have a condition called IgA deficiency
- Have a history of heart or blood vessel disease
- Have had blood clots or thick blood
- Have been immobile for some time

CUTAQUIG can cause serious side effects. If any of the following problems occur after starting CUTAQUIG, contact your HCP or call emergency services. If any of the following problems occur during CUTAQUIG infusion, stop the infusion immediately and contact your HCP or call emergency services:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting, or dizziness. These could be signs of a serious allergic reaction
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem
- Chest pain or trouble breathing, or blue lips or extremities. These could be signs of a serious heart or lung problem
- Fever over 100°F. This could be a sign of an infection

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

What should I tell my healthcare provider before using CUTAQUIG?

Talk to your healthcare provider about any medical conditions that you have or have had.

Tell your healthcare provider:

- That you are taking CUTAQUIG before you get a vaccination, as vaccines may not work while you are taking CUTAQUIG.
- About all of the prescription and non-prescription medicines you take, including over-the-counter medicines, dietary supplements, or herbal medicines.
- If you are pregnant, plan to get pregnant, or if you are nursing because CUTAQUIG might not be right for you.
- If you have diabetes. If you need to do glucose testing, your healthcare provider may tell you to use a different way to monitor your blood sugar levels on the day that you receive a CUTAQUIG infusion. Some types of blood glucose testing systems (glucometers) can falsely interpret the maltose contained in CUTAQUIG as glucose. If you are uncertain, ask your healthcare provider which glucose testing system you can use while using CUTAQUIG.

The most common side effects that may occur with CUTAQUIG are:

- Infusion site reactions (including but not limited to redness, swelling, itching, fluid in tissue, pain, mass, bruising)
- Headache
- Elevated body temperature

One or more of the following possible side effects may occur at the site of infusion; these may go away within a few hours and are less likely after the first few infusions:

- Mild or moderate pain
- Redness
- Itching

These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away. If you encounter any problems or experience side effects during or after the infusion, contact your healthcare provider. When doing so, keep your treatment diary or logbook with you to be able to give all necessary information.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

This brief summary is based on the CUTAQUIG Prescribing Information (October 2021).

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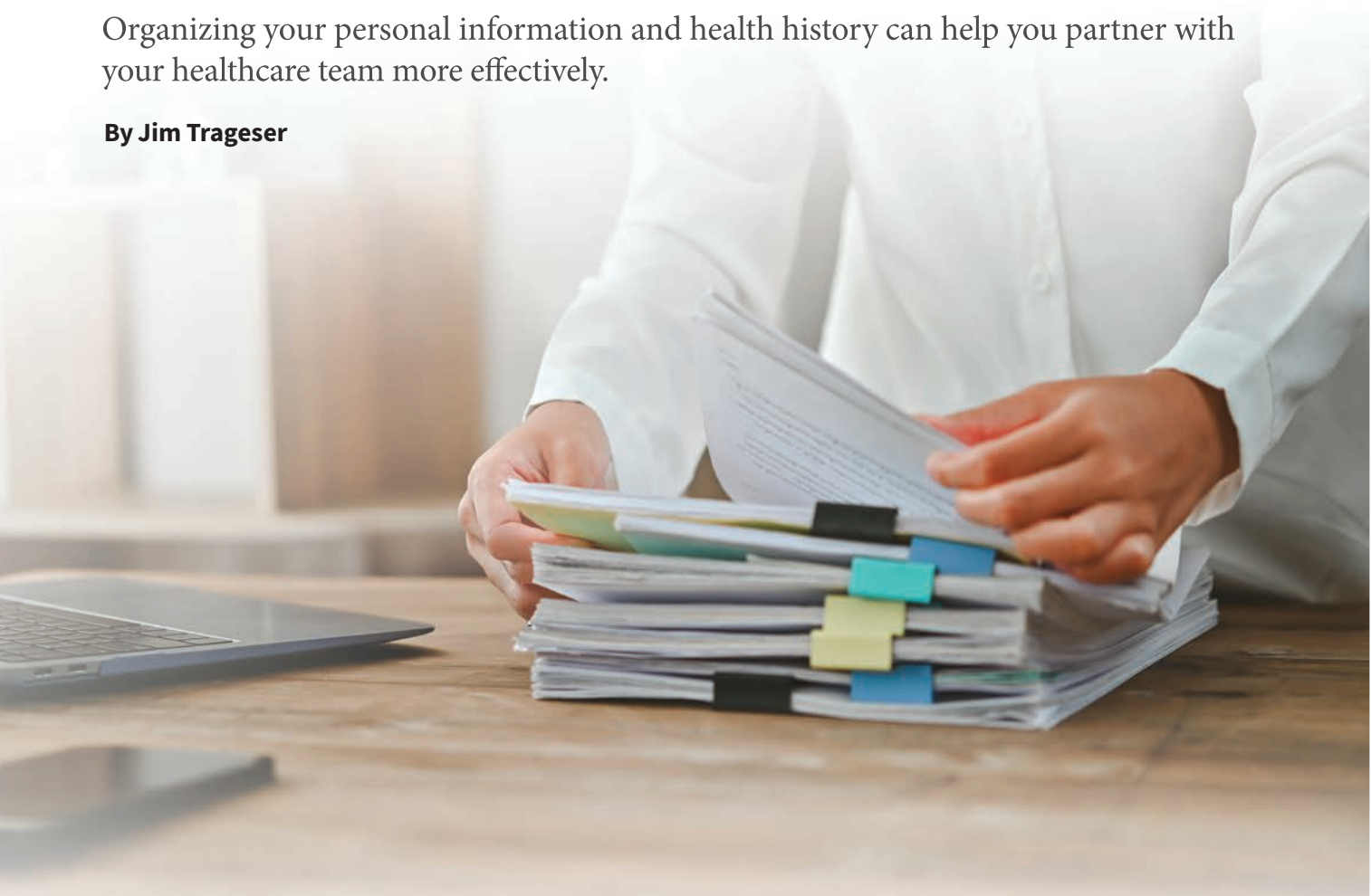
Managing Your Medical Records and Life Documents

Organizing your personal information and health history can help you partner with your healthcare team more effectively.

By Jim Trageser



IF YOU ARE living with a serious chronic medical condition, you have a lot of records to manage! A calendar full of clinical visits, lab tests, imaging appointments and referrals can create a trail of paperwork that can seem overwhelming. Keeping track of your medical records is an important part of managing your health, and with a bit of planning, the paper trail can be organized and tracked without adding to your stress level.

There are many benefits to investing time and energy into organizing your medical records. For one thing, most of us will change practices at some point in time (moving to a new city, getting a new job with a different insurance plan that the old practice doesn't accept, etc.). Your new practice may request records from a previous practice, so it is helpful for you to have them at the ready. When changing medical, dental or eye practices, be sure to take a copy of your records with you! (Note: State regulations oversee how long a facility must keep records, and those can vary from state to state. When making a change, make sure to ask how long the practice will keep your records.) Also, having copies of your health records helps ensure you are billed only for services you received. Further, it helps you check your providers' work. While doctors are highly educated, they are still human, and just like the rest of us they can make mistakes: forgetting a lab test was recently performed, overlooking that they recently had you switch prescriptions based on negative side effects, etc.

It's important to keep medical records and other life documents organized and up to date to effectively partner with physicians in managing your health. Let's break down what records and documents to keep, why to keep them and how to best store them.

What Are Medical Records?

According to the National Institutes of Health, medical records are any documents that track events and transactions between your healthcare providers and you, the patient, and include personal information on diagnoses, procedures, lab tests and other services.[1] The Health Insurance Portability and Accountability Act of 1996 (better known as HIPAA) and the follow-up 21st Century Cures Act (2016) give patients an absolute legal right to copies of every medical record kept on them, not only by their doctor or hospital, but also by laboratories, physical therapists, dental offices and eye care providers.[2] Following is a list of records you should keep copies of:

• *Encounter notes.* The initial records created when a patient visits a doctor, either in-person or via video conference or telephone, are notes the clinician takes during that visit, whether's it's a consultation or an examination (or both). Notes are typically made using the SOAP (Subjective, Objective, Assessment, Plan) format (Figure).

• *Encounter summary*. At the conclusion of your clinical visit, you are likely to be given a printed summary of what was discussed during the visit and the plan for moving forward, which details new prescriptions, lab tests, imaging appointments or referrals to a specialist or therapist. Also, your prescribing physician or the pharmacist will provide you with a detailed information sheet on any new prescription with information on dosage, potential side effects and possible interactions with other drugs. You may be given a printed copy of the visit notes upon conclusion of your appointment, or they may be posted electronically to your online patient portal; different medical groups handle this differently. By law, this information must be made accessible to you.[3]

• *Specialist reports*. Specialists generate similar post-encounter summaries, again likely using the SOAP format.

• *Laboratory and imaging results*. When having imaging or lab work done, your physician will receive a report on the results (a printed or digital copy of the X-ray, MRI ultrasound or other image) or a full diagnostic report on the test results: urinalysis, blood work, stool sample, etc. Under the two laws listed above, you are to receive a copy of the same lab report as your doctor.

• *Immunization record*. For children and young adults especially, an up-to-date immunization record is important to document vaccines received, which indicates vaccines that have been received and prevents against receiving repeat vaccines. (Many states now require an immunization card to enroll in school; keep this with your other medical records.)

• *Prescription history.* Keep a detailed list of prescription medications you have taken or are taking, including name, dosage, date of last refill and next refill and amount paid.

• *Dental records*. Keep a documented history of your overall oral health, including clinical exam notes, past treatments, X-rays, cleaning record, cavity reports and a list of major procedures.

A succinct timeline of major health events is quicker to read than years of lengthy notes.

• *Vision records*. Keep a record of past eye exams, eye conditions, surgeries, injuries, vision problems, prescription history, etc.

• *Billing history*. Keep track of what you have been billed and what you have paid, including billing for physical therapists or mental health practitioners.

Note: Some clinical notes are exempt from HIPPA and the 21st Century Cures Act, including those kept by a mental health therapist during patient visits and any records generated in the course of preparing for a legal or administrative process.[2]

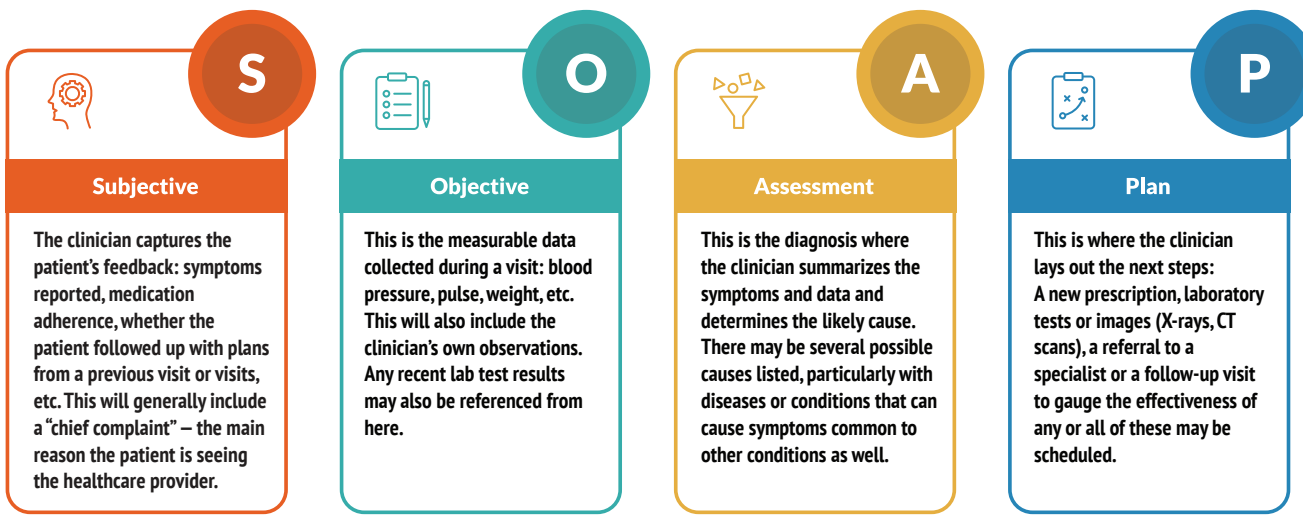
What Are Other Life Documents?

In addition to your medical records, other important documents that may be requested or useful during a medical visit (office visit, urgent care, hospitalization) include government-issued identification, insurance cards, advanced directives and, if needed, medical power of attorney. These documents provide valuable information about and protection for you and your loved ones. Keeping copies of them with your medical record can save time and reduce stress should a major health event happen.

In addition, Johns Hopkins Medicine suggests keeping

The SOAP Method

The industry standard for taking notes during a patient visit is known as "SOAP": Subjective, Objective, Assessment and Plan. The SOAP method was adopted nearly a half-century ago to help doctors, nurses and other clinical staff consistently capture all relevant information during patient visits:



copies of the following:

• *Personal health history.* While your physician will have access to your current records, consider creating a succinct timeline of major health events, which is quicker to read than years of lengthy notes. Include any surgeries you've had in the past, and any other hospitalizations. Also write down your prescription history, including past prescriptions you're no longer on and why you were taken off those prescriptions. This can help your doctor avoid any drug interactions or allergic reactions.[4]

• *Family health history*. Detail any health issues of your grandparents, parents and siblings. Keep this document with your medical records, and be sure to update it as your family members' encounter new medical challenges.[5]

• *Current provider contact information*. Make a list of the phone numbers of all medical providers you are currently seeing, including your general practitioner and any specialists such as physical therapists, dentists and, if relevant, eye doctors. Note what conditions or diseases each provider treats you for.

Isn't My Online Record Enough?

With ongoing advances in computer technology, medical records are more likely to be created and stored by your healthcare providers in digital format, making them available to you (and your healthcare team) anywhere with Internet access. However, some important documents remain primarily in the physical realm: Social Security cards, driver licenses, passports, health insurance cards, etc. Other documents such as advanced directives, for instance, may exist in either digital or physical form.

Since these documents are not stored in your physician's electronic health record, consider creating a place (digital or physical) to keep all of your information in one place. Hard copies of your personal identification cards, health insurance information and advanced directives can be scanned into your own digital repository. You can even make it available on your smartphone or tablet. If you are interested in having everything on your cell phone, the technology is affordable and relatively easy to use. If you prefer the traditional approach, you will likely need a small file box and a series of manila folders.

Healthcare providers are not legally required to digitize patient records, and smaller medical practices or those outside large cities may still maintain patient records in print format. Even those, however, can be scanned in and saved in pdf format with almost any retail computer printer or even a cell phone camera.

HIPAA and Privacy

While having access to medical records allows patients to be fully informed in teaming with doctors to navigate health challenges, health records are also sensitive and should be kept private. Congress passed HIPAA to ensure only people who must access our records in the course of providing treatment or billing for services rendered can do so. There are significant penalties for any medical employee who overtly violates the HIPAA privacy provisions.

In the case of minors or adults who need assistance making informed healthcare decisions, a personal representative — parents or guardians for minors, or whoever holds medical power of attorney in the case of adults — will have the same right to access records as the patient. (Some states, such as California, have passed laws that limit which medical records parents can see once a child reaches a certain age, usually in the teens. A medical power of attorney may be needed in those states for a parent to see their child's records to assist them in making informed decisions.)

In addition, HIPAA prevents labs from blacking out any information on the reports sent to patients — even disconcerting results that a doctor would have delivered in the past.

Organizing It All

The main thing to remember is that there is no single "right" way to organize your files. Organize them in a way that makes sense to *you*. Some people like to group their information by year, others by type of record (doctor, lab, pharmacy). The main thing is that you organize your records so that you can find them when you need them, and that might be while at the doctor's office or when you are feeling stressed and flustered. Finding what you want quickly should be your guiding principle.

For those whose doctors keep their records digitally, you will likely have a secure account where you can log in and access them. Make sure you can remember your login and password information if you are relying on accessing the digital copies from your phone or tablet during a visit. One benefit of a digital system is that the records are organized for you! Kaiser Permanente, for instance, a large healthcare provider in the western United States and Washington, D.C., area, organizes patient records into notes and summaries from recent visits, lab results, immunizations, billing and pharmacy history. Within each section, the records are sorted in reverse chronological order (newest first). However, there is no option to save each entry in the Kaiser Permanente system. They can be printed, however, and there are free pdf filters for both Mac and Windows that allow you to either save a page as a pdf or print to a pdf file and save it locally. Other medical providers may have different options that allow you to download records to your hard drive.

But even if your doctor has your full medical history in digital format, you will also need to have your other life documents saved locally. If you like having everything on your smartphone, create a directory in your documents folder for your medical records. (Since pdf files can be quite large, you may want to look at adding additional storage via a SIM card, which most smart phones accommodate and are fairly inexpensive.) Organizing your medical records within a smartphone directory will often involve creating different subdirectories for easy sorting: doctor notes, prescriptions, lab work, bills, insurance forms, etc. Whether scanning documents into your computer and then transferring them to your phone or using the cell phone camera as the scanner, give each document an easily recognizable file name for quick and easy access.

If your doctor does not digitize medical records, or if you simply prefer having paper copies of your records, you can get a small plastic file box and manila folders from any office supply store.

Whether paper or digital, the number one way to keep your records useful is to keep them current. Even if your doctors are all digital, be sure you actually log in and review all records to ensure they are accurate. Check post-encounter notes, bills, pharmacy records, lab work, etc. When you feel something is inaccurate, reach out immediately to request a correction.

Knowledge Is Power

Again, having current, accurate and organized medical records gives you quick access to your health history. When discussing symptoms, diagnoses or treatment options with your doctor, having that data in hand better allows you to give informed input — and to serve as a true partner with your physician. IG

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Retirement and Beyond:
Planning for the Golden Years While Living with Chronic Illness

By planning for transitions later in life, older adults with chronic conditions will be better equipped to ensure their needs are met.

By Cynthia Perry

RETIREMENT CAN be a joyful phase of life, but it can also bring unique challenges. Retirees often find themselves helping adult children transition to independence, assisting aging parents, transitioning to Medicare and, perhaps, working part time. All of these transitions can be even more complicated when managing the day-to-day challenges of chronic illness. As part of managing these transitions, it's important to evaluate assisted and independent living models, Medicare options, long-term care options and legal protections to take today to ensure peace of mind tomorrow.

Where and How to Live?

The decision about where to live during different phases of life is very personal. Important considerations include:

- The timing for downsizing or preference for aging in place
- Space needs for children, grandchildren or aging parents
- Freeing home equity to fund retirement
- Desire for social interaction
- Healthcare considerations, especially if driving is no longer possible

Healthcare considerations are paramount to decisions about living situations. More than 90 percent of adults over age 65 have at least one chronic illness, and almost 80 percent have two or more chronic illnesses.[1] There are many types of living situations designed to help older adults live well, each offering different levels of support.

Fifty-five-plus communities are planned subdivisions reserved for adults over 55. These developments often offer amenities and programs tailored to the needs and interests of older adults, such as social activities, fitness centers, swimming pools and more. While grandchildren may visit, children are not allowed to live there long-term, and activities for children will likely be limited since communities cater to active older adults.

Independent living communities are also usually for those 55 years and older and offer varying levels of support. They may offer detached homes or apartment living; some allow residents to purchase a home, while others comprise rental units. Many apartment rental arrangements include all utilities, basic cable and Internet, an on-site salon and barbershop, local transportation to shops and appointments, shared common spaces and planned activities (some even include meals), all for one single monthly payment. When the costs of maintaining a home are added up, these communities can be surprisingly affordable. It is remarkable how many amenities independent living residences can include in their monthly fees.

Assisted living facilities are appropriate for seniors who need help with activities of daily living but don't need round-the-clock care. These residences provide more personalized support than independent living, but less intensive support than nursing homes. Depending on the community, help may be available for medication reminders, dressing and meals. These facilities do not have skilled nurses on staff, so they do not dispense medications, monitor blood sugar or give injectable medications to residents.

Skilled nursing facilities or nursing homes provide round-the-clock medical care. They have a doctor on site and lower staff-to-resident ratios than assisted living. On-site skilled nurses can dispense medications, monitor blood sugar and blood pressure, and handle issues related to incontinence. While Medicare and Medicare Advantage may pay for short-term stays in skilled nursing facilities for rehabilitation purposes, payment usually ends after 30 days. At that point, patients or their families must pay for expenses on their own, and this level of support costs hundreds of dollars per day.

Long-term care insurance can help with these costs after health insurance benefits end. However, pre-existing medical conditions can make it difficult to obtain this insurance. A wide array of options exist for long-term care coverage. Many policies have limits on how long or how much they will pay. Some policies will pay expenses for a few years, while others will pay expenses for life.[2] Insurance brokers can help people find the best options for their needs.

Healthcare considerations are paramount to decisions about living situations.

It's important to know that even when insurance pays for long-term care, immune globulin (IG) therapy is generally excluded from the medications and therapies covered in a skilled nursing facility. Long-term care insurance will likely also exclude IG therapy. Currently, the Immune Deficiency Foundation is actively advocating for IG therapies to be included for patients in these settings.[3]

For this reason, it may be better for people prescribed IG therapies to look into senior living facilities that can offer nursing-home support in private apartments. In these facilities, spouses can remain together and pay for only the level of assistance each one of them needs. Such facilities charge fixed monthly rates that can be surprisingly affordable when compared to the exorbitant daily rates charged by nursing homes. Another option to explore is private care at home.

Continuing care retirement communities offer a range of living situations, from independent living to nursing home care, and even hospice. It's possible to change the level of support received while staying in the same residence, though it may be necessary to move homes within the facility as needs change. These communities can be a great option for people who expect their needs may increase as they age.

Medicare vs. Medicare Advantage

Medicare currently begins at age 65, even for people who haven't reached full retirement age. There are many Medicare options, and it can be useful to engage a health insurance broker to help understand which selection is best for individual circumstances. Healthcare providers may be able to recommend a reputable broker, and friends and family may be able to offer contact information for brokers they trust. State Health Insurance Assistance Plan (SHIP) counselors are also a good resource for advice. They are available in all 50 states, Washington, D.C., and U.S. territories.[4]

Original Medicare (also known as Part A and B) is often a good choice for those treated with IG. Medicare covers SCIG and IVIG at home or in an infusion center. However, pharmacies, nursing agencies and hospitals must all be in-network for Medicare. Hospital stays are paid under Part A, while Part B provides for outpatient services and supplies, including IG medication, supplies and nursing and pharmacy support. Most Medicare benefits don't require prior authorizations, but home IVIG and certain other situations may necessitate prior authorizations.

Most people who choose original Medicare (sometimes called "red, white and blue" due to the color of the cards Medicare issues) also purchase a pharmacy plan (Part D) because prescriptions are not included in Medicare Parts A and B. Medicare offers online tools to help select the best insurance for each situation. The tool will consider prescription costs and preferred pharmacies, along with premiums, deductibles, co-pays and out-of-pocket maximum expenses (www.Medicare.gov). Brokers can also help with Part D options.

In addition, original Medicare pays only 80 percent of patients' bills after the annual deductible is met. For this reason, many beneficiaries elect to purchase a "gap plan" to pay the balance of bills. There are many different levels of benefits and monthly cost options. Again, Medicare offers online tools, and a broker can help beneficiaries understand the best option for them.

Medicare Advantage Plans, also known as Medicare Part C, are managed by private insurers and include extra benefits such as fitness clubs, dental and vision. However, these policies can limit the choice of providers and often require prior authorizations, which can be a problem for those with rare, chronic conditions. Some Advantage plans may have narrower formularies or restrict beneficiaries' ability to continue with their current doctors, specialty pharmacy and even IG brand or infusion method. These policies may also come with high out-of-pocket maximums that must be paid every year before insurance pays.

Receiving Medical Care

Another important consideration for older adults is how to get the medical care they need, especially if they're no longer driving.

Primary Care at Home is available to seniors in some parts of the country, especially larger metro areas. With this program, patients are treated by physician assistants or nurse practitioners who practice under a licensed doctor. These healthcare providers keep costs down by not having the overhead of medical offices. Sometimes, individuals must have two or more chronic conditions to qualify for these services.

Senior clinics may also be a good option for healthcare. Some clinics partner with Medicare Advantage plans and may offer a variety of specialists, in addition to primary care, in a single office. These clinics may even offer nutrition and other wellness programs, along with medical rides, for seniors.

Telehealth can be an option for some primary care, specialist care and even some urgent care situations. Generally, the provider must be licensed in the state where the patient is located during the appointment. Some providers are licensed in multiple states, but most are not.

Mobile labs may be available, especially in larger metro areas. With these, phlebotomists draw blood at the individual's home and take it to labs for processing. Medicare may pay the costs for those who are homebound.

Patient advocacy coverage by Medicare started in 2024.[5]

Some private insurance companies also offer nurse navigators or case managers. These providers can help patients with complex medical issues better navigate the healthcare system.

It's important to know that even when insurance pays for long-term care, immune globulin (IG) therapy is generally excluded from the medications and therapies covered in a skilled nursing facility.

State and local agencies for aging are good resources, especially for seniors with limited financial means. These agencies can help constituents access programs and funding to get the care they need. One example is the Program of All-Inclusive Care for the Elderly offered in 33 states and Washington, D.C. This program provides nursing home support for seniors who want to stay at home. Rides to medical appointments, Meals on Wheels and other programs financed by state and local governments may also be available to help seniors.

Legal Documents

Beyond will and estate planning, there are other legal documents related to end-of-life planning that are important to have in place and updated regularly.[6]

Health Insurance Portability and Accountability Act forms are documents healthcare providers ask their patients to complete. These forms give permission for a provider to talk with family, friends and caregivers. This is different from naming someone as healthcare proxy or medical power of attorney. A healthcare proxy can make decisions only if someone is unable to communicate on their own.

Medical power of attorney is a document that designates someone to make medical decisions in case of a patient's incapacitation. Choosing someone who understands a patient's medical history and is willing to carry out any final wishes is important.

An advance healthcare directive or living will outlines what types of treatment are wanted or not wanted in various medical scenarios. This document includes preferences for resuscitation, ventilation or tube feeding. There are sample forms online, and estate planning lawyers are well-versed in the legal options for emergency medical care.

Do not resuscitate is a legally binding form telling emergency responders not to perform CPR on a patient. This form must be signed by a doctor to ensure it is medically appropriate and is not legally binding without a doctor's authorization. First responders are trained to look for this documentation on refrigerators.

A financial power of attorney and living trust name and instruct a person, called the trustee, to hold and distribute property and funds when someone is no longer able to manage their own affairs. Anyone can become incapacitated at any time, and these documents ensure a patient's financial and medical needs can be met.

A Final Word

People living with chronic illness should develop self-advocacy skills for navigating the healthcare system. These skills are valuable in retirement and beyond when informed choices, proper insurance and advance planning can ease life transitions. Discussing preferences with loved ones is important. Having a binder with legal documents, medication lists and schedules, healthcare providers and other key documents and contacts in one place is vital, as is letting loved ones know where to find them. It's also crucial to revisit living situations and legal documents regularly as life circumstances evolve. IG

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The Pharmacy Prescription Price Puzzle

The high cost of medicines, including IG therapies, in the U.S. is due to a highly complex system in which multiple stakeholders interact. Fortunately, understanding how pricing works, as well as the implementation of policy developments, does help.

By Surayyah Morris, PharmD

PRESCRIPTION DRUG costs have drawn far-reaching attention in recent years. For many patients, the price tag of essential medications — from diabetes insulin to cancer biologics and immune globulin (IG) therapy — can be staggering. In fact, a 2020 study estimated U.S. patients spent $358 billion out of pocket on prescription drugs over the previous decade. Additionally, prices of brand-name drugs in the U.S. are significantly higher than in nearly all other high-income countries.

Several factors contribute to the complex high drug cost puzzle: the intricate supply chain (manufacturers, wholesalers, pharmacies, patients), the opaque role played by intermediary pharmacy benefit managers (PBMs) and erratic pricing strategies across retail, specialty and hospital pharmacies. Let's shed light, through examples and policy contexts, on how prescription drug pricing works — and how stakeholders influence it.

Generic, Brand Name and Specialty Biologic Medicines

Generic drug examples:

• Metformin is a common medication for type 2 diabetes. The generic tablet may cost as little as $4 to $10 for a month's supply, both in and out of insurance networks, due to multiple manufacturers and lack of patent protection.

• Atorvastatin is prescribed to lower cholesterol and costs under $10 monthly. Its affordability stems from competition and simplified chemistry.

Branded drug examples:

• Lyrica (pregabalin) is prescribed for neuropathic pain and epilepsy. A 2025 report indicates a one-month supply costs around $300 to $400, even with insurance.

• Harvoni (ledipasvir/sofosbuvir) is a hepatitis C treatment. When launched, it cost over $90,000 for a 12-week course. Today, while prices have dropped significantly, they remain around $24,000 to $30,000 and are often still billed to insurers with negotiated rates that patients rarely see.

Specialty/biologic drug examples:

• Humira (adalimumab) is prescribed to treat inflammatory diseases such as rheumatoid arthritis. The list price per two-week injection was around $2,800, totaling more than $70,000 annually before rebates. Biosimilars have since entered, but list prices remain high, approaching $1,700 per dose, although insurers pay much less after rebates.

• Keytruda (pembrolizumab), a cancer immunotherapy drug, costs $150,000 to $180,000 per patient per year, depending on the dosing schedule and indication.

• Lantus (a brand name for insulin glargine) was once priced around $275 per vial, but even replacement biosimilars (e.g., Basaglar) range from $300 to $350. Recent insulin price caps and manufacturer discounts have reduced costs for many patients, but list prices remain high.

• IG therapies are medicines derived from human plasma, prescribed to treat patients with primary immunodeficiency disorders, autoimmune diseases and certain neurological conditions such as Guillain-Barré syndrome, chronic inflammatory demyelinating polyneuropathy and myasthenia gravis.

There are two main formulations of IG therapy: intravenous IG (IVIG), which is delivered via infusion in a hospital, outpatient clinic or home setting; and subcutaneous IG (SCIG), which is self-administered at home, usually more frequently and in smaller doses

The production of IVIG and SCIG is complex, expensive and time-consuming. It requires pooled plasma from thousands of donors. The manufacture of the product involves viral inactivation, purification and cold-chain logistics. And, it takes between four and 12 months from plasma collection to when a final product is available, depending upon the manufacturing process.

The high cost of IVIG and SCIG products are due to a limited amount of human plasma that is dependent on voluntary donors that require initial and ongoing screening, a lengthy and labor-intensive manufacturing process, strict regulatory requirements for manufacturing and growing demand, coupled with a limited supply.

Average wholesale prices for IVIG and SCIG products typically range from $175 to $1,000 per gram, with total doses depending on patient weight and indication. For example, a 70 kg patient needing 2 grams/kg for an autoimmune flare equals a 140 gram total dose, with a total cost of $14,000 to $22,400 per treatment, not including administration or facility fees.

Retail pharmacies such as CVS, Walgreens and independent outlets are the most visible part of the supply chain.

PBMs: Gatekeepers of Cost

PBMs are intermediaries that manage drug benefits for insurers, employers and Medicare Part D. Their role includes:

• Designing drug formularies that determine which medications are covered and at what cost to patients

• Negotiating rebates and discounts with drug manufacturers in return for favorable formulary placement

• Contracting with pharmacies

• Managing patient cost-sharing via tier systems (e.g., generic, branded, specialty)

Manufacturers offer rebates to PBMs — often secretive and high — after patient purchases. For example, Humira likely had rebates near 50 percent, meaning a $2,800 list price might drop to $1,400 net for PBMs. However, patients or plan beneficiaries are often responsible for a coinsurance percentage of the list price, not the net price, so costs might remain high for them.

Some PBMs practice spread pricing: charging insurers more for a drug than what they reimburse pharmacies, retaining the surplus. This lack of transparency has prompted state-level investigations and calls to regulate the practices of PBMs.

PBM utilization of management tools can push providers and patients toward generics or biosimilars. Some tools include:

• Step therapy: This requires a trial of medications in a certain order (usually the lower-cost drugs to begin and increasing according to cost and effectiveness).

• Prior authorization: This requires extra convincing of the benefits vs. risks of a medication compared to the chosen formulary option/gold standard.

• Quantity limits: This occurs when insurers will cover only a certain amount of medication in a specified amount of time (e.g., limited to a 30-day supply at a time, or medication covered only for X number of months before increases in cost/co-pay increases or coverage denial).

• Exclusions: Some medications can be excluded from a formulary in lieu of more expensive branded drugs.

While cost-effective, when using these tools, there is a risk of delayed care or limited patient choice.

The Role of Retail Pharmacies

Retail pharmacies such as CVS, Walgreens and independent outlets are the most visible part of the supply chain. Their (somewhat oversimplified) role includes dispensing medications, clarifying dosage and side effects and providing immunizations.

But retail pharmacies also contract with PBMs to be in-network for reimbursements. PBMs typically reimburse retail pharmacies at a negotiated rate. Pharmacies cover medication costs, dispensing, overhead and personnel. The PBMs' reimbursement less the pharmacies' cost determines profitability. Pharmacies may struggle with reimbursements lower than acquisition costs (a common complaint in rural/independent settings).

Retail chains use expanded services to offset low drug margins, including medication therapy management, chronic care education, vaccinations and point-of-care testing (flu, strep, COVID), which are reimbursed separately.

Many large retail pharmacies offer GoodRx-style discount programs or price-matching online, allowing uninsured or cash-paying customers to buy select generics for $4 to $10 a month. Unfortunately, participation in PBM networks can limit them from offering lowest cash quotes to insured patients.

The Role of Specialty Pharmacies

Specialty pharmacies handle high-cost, high-complexity medications that often require special handling, ongoing coordination and patient monitoring. These include:

• High-cost medications (often biologics and oncology) and supplies: With these, there is limited competition, and many are biologics with no generic equivalent. There are also distribution complexities; some medications are distributed exclusively through specific pharmacies. In addition, rebate structures make list prices high, while net payer prices drop, but patient cost-sharing remains tied to list price.

• Medications that require patient education, adherence support and insurance navigation

• Medications that require special handling (e.g., refrigeration, sterile compounding, infusion)

The Role of Hospital Pharmacies

Hospital pharmacies dispense medications within inpatient and outpatient hospital settings. Their role and cost dynamics are considerably different. Inpatient drugs are bundled into hospital charges. Outpatient clinics bill insurers separately for outpatient administration and drugs. Hospitals buy drugs through group purchasing organizations (GPOs), which negotiate large-volume discounts and rebates. Hospital pharmacies manage inpatient care (administering IV antibiotics, chemotherapy, nutraceuticals and specialized medications) and outpatient 340B clinics, which provide care for low-income or underinsured patients. The 340B program also allows hospitals to purchase drugs at 20 to 50 percent discounts, yet reimbursement may be near full price.

The Distribution Chain of IG Therapy

Manufacturer to wholesaler. Under this distribution chain:

• IG products are sold to licensed wholesalers or specialty distributors.

• These intermediaries ensure cold-chain maintenance (2°C to 8°C), which is critical for biologic stability.

• Prices are negotiated based on volume purchasing; some GPOs and large hospital systems receive better rates.

Wholesaler to pharmacy or infusion center. Under this distribution chain, wholesalers may charge markup fees that are passed downstream to pharmacies. IVIG is usually purchased by hospital or infusion pharmacies and then administered in outpatient centers, hospitals and in patients' homes. SCIG is usually shipped by specialty pharmacies directly to a patient's home (with necessary training, supplies and nursing support).

Pharmacy to payer (insurer or Medicare). Under this distribution chain, pharmacies bill the insurer based on acquisition cost, dispensing and handling fees.

Patient cost. Patient cost-sharing depends on the insurance plan:

• Medicare Part B covers IVIG in physician offices and at home (with 20 percent coinsurance), typically covered by a Medicare supplemental plan, any secondary insurance or Medicaid, as applicable. Medicare Part B also covers SCIG at home; however, coverage for both IVIG and SCIG is diagnosis-dependent.

• Medicare Part D covers IVIG and SCIG, which enables patients to infuse in the home setting. Prior authorization is required. Medicare Part D can cover only IVIG and SCIG when it is ordered for an FDA-indicated or an off-label diagnosis, which has a positive compendial reference in either of two Medicare-approved reference sources (DrugDex or AHFS).

• Commercial plans often have deductibles and out-of-pocket fees depending on the plan. For example, a patient might face $3,000 to $5,000 out of pocket per year without supplemental coverage. Once again, co-pay assistance or manufacturer programs can reduce the burden for eligible patients.

Where IG is administered dramatically affects cost. Payers increasingly prefer home infusion due to lower total costs,

improved patient convenience and comparable efficacy and safety. Some insurance companies require "site-of-care optimization," pushing patients to move from hospital outpatient sites to infusion centers or the home.

Coverage for IG Therapy

Prior authorization is almost always required for IG therapies, requiring diagnosis confirmation, documentation of failed alternative treatments and periodic renewal. Insurers may also require step therapy, which requires patients to be prescribed IVIG before covering SCIG. This delays care and frustrates clinicians. It not only becomes discouraging, but it contributes to an inability to provide proper care. In addition, PBMs may impose pharmacy choice restrictions, mandating the use of preferred specialty pharmacies, which blocks independent pharmacies or hospital-owned specialty programs from dispensing IG products.

Policymakers, payers and manufacturers are increasingly focused on strategies to manage these costs and home infusion, standardizing prior authorization protocols, promoting transparent pricing and supporting co-pay assistance.

Currently, IG therapy is a higher-cost outpatient treatment. Due to the complexity of production, logistics and administration, the cost burden is significant for insurers, hospitals and especially for patients with inadequate coverage. Ultimately, access to lifesaving IG therapy must balance clinical benefit, supply constraints and sustainable financing.

The Impact of Medication Costs on Patients

Unfortunately, transparency is limited for patients who rarely know how much of their bill is profit vs. cost. For instance, with coinsurance, rather than flat co-pays, patients may owe 20 to 40 percent of a $10,000-per-month drug, or $2,000 to $4,000 per month. Patients can seek financial assistance or assistance from co-pay foundations, which is complex but sometimes necessary.

Policy Developments to Contain Medication Costs

Numerous policy efforts have been put in place to help with the high costs of medicines, including:

- State laws and Centers for Medicare and Medicaid Services (CMS) rules requiring PBM rebate disclosures
- A CMS rule (in mid 2024) that requires list prices of drugs to be posted in television ads
- The No Surprises Act for hospitals that now includes medication pricing
- Out-of-pocket caps
- Reduced patient cost with biosimilar adoption and intention to improve biosimilar access
- Importation and drug reimportation
- Value-based pricing and alternative payment models implemented by insurers and Medicare such as outcomes-based agreements with manufacturers (e.g., manufacturer refunds if drug fails to meet performance)
- Netflix-style subscriptions (e.g., state deals for hepatitis C drugs) that offer flat fees for unlimited volume

A Highly Complex System

Pharmacy prescription costs reflect a highly complex system in which multiple stakeholders — manufacturers, PBMs, insurers, retail/specialty/hospital providers and patients — interact. Generics offer low-cost options when there's competition. However, branded and specialty biologics often carry massive list prices, with patients typically stuck paying coinsurance based on those prices. PBMs wield enormous pricing power through rebate and spread-pricing strategies, leading to counterintuitive outcomes in which lower net prices don't translate to lower patient costs. Meanwhile, retail and hospital pharmacies operate on thin margins, while specialty pharmacies manage immense complexity and cost.

From price transparency and out-of-pocket caps to biosimilar promotion and PBM oversight, reforms are underway. While positive, more robust solutions may be needed to align the true cost of drugs with patient affordability and system sustainability. Ultimately, the goal is ensuring safe, accessible and affordable medications so patients aren't burdened by the very medicines meant to heal them.

So, why does everything cost *so much*? The world may never know, but at the very least, we can make understanding the processes work in our favor. After all, you're strong enough to warrior your way through, remember that. IG

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Must-Have Kitchen Tools When Living with a Chronic Illness

Cooking isn't easy when you don't feel good or your body doesn't cooperate, but these modified gadgets can help you get the job done and feed yourself well.

By Emily Cooper, RDN

LIVING WITH a chronic illness comes with daily challenges. Issues like chronic pain, fatigue or limited mobility can make everyday tasks difficult and exhausting. Even preparing a simple meal can feel daunting, especially when the environment and equipment aren't designed with your needs in mind. Luckily, there are a number of kitchen tools that can help make these everyday tasks easier and safer. Following are tools, tips and equipment that can change your cooking routines for the better.

Food Prep Tools

When living with a chronic illness, traditional kitchen tools aren't always accessible or effective and can make food preparation difficult and draining. However, there are many specialized tools available that make preparing food easier, more efficient and much safer. Look for items with ergonomic design, improved grip, enhanced safety and motorized functions. Lots of options are out there:

- *Non-slip cutting board*: A safe and sturdy area to cut on is key for any home chef. Look for a cutting board with a non-slip or suction cup bottom, which makes food prep easier and safer for those with limited hand function.
- *Cutting glove*: Cutting gloves add an extra level of safety for all, but especially for those with limited hand dexterity or sensation. Wearing a cutting glove on the hand you are not cutting with allows you to grip the food you are cutting, without having to worry about risking injury.
- *Rocking knife*: Often referred to as a "mezzaluna," a rocking knife is a curved blade fitted between two handles (one on each side of the blade) that utilizes a rocking motion to cut. This design puts less strain on the hands than a traditional straight knife.
- *Automatic can opener*: Handheld can openers require a lot of grip strength and dexterity, but motorized versions put much less strain on your hands. Many also create smooth, blunt edges, making open cans safer to handle as well.

• *6-in-1 opener*: Limited grip strength makes opening sealed food items challenging. A 6-in-1 opener opens jars, bottles and pull tabs, cuts open boxes and bags and removes foil lids with ease.

• *Palm peeler*: A palm peeler is an ergonomic alternative to a traditional vegetable peeler. It attaches to your finger and sits in the palm of your hand, making it more comfortable to use with less hand strain.

• *Mini food processor*: While full-sized food processors can be helpful for large amounts of chopping, they are less effective for smaller amounts; they are also heavy and cumbersome to carry and set up. A mini food processor, on the other hand, may be much more accessible and useful for chopping or dicing ingredients. Instead of large amounts of food, it can handle smaller jobs such as chopping one onion, one bell pepper or a few cloves of garlic. Most of the parts are dishwasher-safe, making it easy to clean up as well.

• *Vegetable chopper*: Vegetable choppers make prepping vegetables or fruits easier and less time-consuming. They often come equipped with multiple blades for different applications, including rough chop, fine dicing, slicing and grating. Vegetable choppers do require some manual cutting to get the veggies into more manageable sizes, but may be worth it since they limit how much extra chopping is required. Another caveat is that they require a good amount of energy to use, so they may not be the best option for anyone concerned about fatigue or muscle weakness.

• *Tongs*: This basic kitchen tool is loved by professional chefs and home chefs alike. For people with limited strength or mobility, tongs can offer a stronger grip while requiring less strain on the hands. Look for different sizes that also have added padding for hand support and silicone tips for extra grip.

• *Reaching tool*: Also known as a grabber, reach extender or picker-upper, reaching tools are great for using throughout the home, including in the kitchen. Reaching tools can be used to grab light items on higher shelves or for picking items up off of the floor. These can be especially helpful to patients with limited mobility or range of motion. However, keep in mind the reacher tool should be used only for lightweight items that don't come with a risk of shattering or breaking.

• *Modified prep bowls*: Prep bowls made of heavy glass or ceramic can get really heavy and cumbersome. Prep bowls made of a lightweight material such as plastic or stainless steel are easier to maneuver around the kitchen. Opt for bowls that suction to the countertop or have a non-slip bottom to prevent them from moving or tipping over.

• *Anti-fatigue kitchen mat or rolling stool*: Spending a lot of time standing in the kitchen can be taxing on the body, especially when energy is limited. Using a non-slip, anti-fatigue kitchen mat in the areas you spend the most time in, such as in front of the sink or stove, can offer more support and comfort. Alternatively, using a stool with wheels and back support can help you move around the kitchen without requiring long periods of standing.

Cooking Tools

Using the stove top or the oven can pose challenges for those living with chronic fatigue, pain or limited mobility, but that doesn't mean cooking at home has to be off limits. Here are some appliances and tools that can make things easier while also being safe.

• *Convection oven or air fryer*: Transferring heavy dishes of hot foods in and out of the oven requires a lot of energy, and poor ventilation and hot temperatures can lead to symptoms such as overheating and fatigue. Utilizing a countertop convection oven or air fryer can be a safer, more accessible option. It can be a great alternative to a traditional oven for cooking smaller meals, reheating leftovers and cutting down on cooking time. However, it is much smaller than a regular oven, so cooking for a large group or making multiple items at once may be more difficult. It also takes up counter space, which is important to consider if space is limited.

• *Electric skillet*: An electric skillet is a great alternative to a traditional stove. It can be a great option for those with difficulties standing for long periods of time, those who use a wheelchair or those who prefer to cook while seated. Look for an electric skillet that has an auto-off feature for an added level of safety. It is also portable and can be stored when not in use, freeing up counter or tabletop space.

• *Countertop multi-cooker*: While slow cookers are convenient for hands-off cooking, they can be heavy and tedious to clean. A countertop multi-cooker is a useful alternative since it can be used for a number of different cooking methods. Most can be used as a pressure cooker or slow cooker, and can also cook grains like oatmeal and rice. The liner is much lighter than a ceramic slow cooker insert, and inserts are dishwasher-safe, making them relatively easy to use and clean. Multi-cookers can also be a convenient way to batch cook items such as soup, beans, grains and meats that can be stored and used throughout the week. Look for recipes specifically designed for a multi-cooker to make meal prep and clean up easier.

octagam® 10%

Immune Globulin
Intravenous (Human) 10%
Liquid Preparation

For the treatment of dermatomyositis (DM) in adults

INDICATIONS AND USAGE

OCTAGAM 10% is indicated for the treatment of chronic immune thrombocytopenic purpura (cITP) in adults and dermatomyositis (DM) in adults. For patients with cITP, it is used to rapidly increase the platelet count in the blood to help control or prevent bleeding. For patients with DM, it helps improve muscle function and skin rash.

OCTAGAM 10% is a liquid medication that contains Immunoglobulin G (IgG). OCTAGAM 10% is made from human plasma donated by healthy people. OCTAGAM 10% is given through the vein (intravenously) in a hospital, infusion center, or at home.

IMPORTANT SAFETY INFORMATION

- Do not use OCTAGAM 10% if you have had a severe allergic reaction to IgG or other blood products or have deficiencies of immunoglobulin A (IgA) with antibodies to IgA.
- OCTAGAM 10% can cause the following:
  - Blood clots in your heart, brain, lungs or other areas of your body
  - Kidney problems, or kidney failure
- Tell your healthcare provider (HCP) if you have an allergy to corn. OCTAGAM 10% contains a type of sugar that is made from corn.
- OCTAGAM 10% can cause the following serious side effects. Contact your HCP if you experience the following:
  - Swelling in your mouth or throat, hives/itching, breathing problems, wheezing, fainting, tightness in your chest, or dizziness. This could be a serious allergic reaction.
  - Decreased urination, swelling in your legs, sudden weight gain, or breathing problems, which could mean kidney failure
  - Pain and/or swelling of an arm or leg with warmth in the affected area, discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens with deep breathing, unexplained rapid pulse, or numbness or weakness on one side of the body; these could be signs of a blood clot.
  - Yellow skin or eyes, dark-colored urine, fatigue, or increased heart rate, which could be signs of a blood problem.
  - Headache, stiff neck, drowsiness, fever, sensitivity to light, painful eye movements, or nausea and vomiting, which could mean an inflammation of the membranes covering your brain or spinal cord
  - Trouble breathing, chest pain, blue lips, arms or legs, and fever, which could be related to a lung problem. This typically occurs 1 to 6 hours following infusion.

OCTAGAM 10% helped patients achieve greater improvement in DM symptoms compared to placebo

In a clinical trial, 95 adults with dermatomyositis (DM) were split into two groups. Group 1 was given OCTAGAM 10% and Group 2 was given placebo. Patients in both treatment groups could continue taking their other medications while they were part of the trial. The clinical trial looked at how patients improved in DM muscle and skin symptoms. Researchers measured 3 levels of symptom improvement after 16 weeks: minimal, moderate, and major.*

*Symptoms were measured on a 100-point scale as measured by the Total Improvement Score (TIS), with 0 being worsening or no improvement and 100 being the most improvement. An improvement of at least 20 points was considered minimal; at least 40 points was considered moderate; and at least 60 points was considered major.

79%

At least minimal improvement
vs 44% placebo
(primary endpoint)

68%

At least moderate improvement
vs 23% placebo
(secondary endpoint)

32%

Major improvement
vs 8% placebo
(secondary endpoint)

Patients treated with OCTAGAM 10% saw
symptom improvement in 35 days†

†Based on measuring median time to (at least) minimal improvement.

Most common drug-related side effects

In a clinical study, more than 5% of patients had the following side effects:

Headache: 42%; **Fever:** 19%; **Nausea:** 16%; **Vomiting:** 8%; **Chills:** 7%; **Musculoskeletal pain:** 7%; **Blood pressure increased:** 6%

$0 Eligible patients may pay as little as $0 with the OCTAGAM 10% Co-Pay Program‡

May reduce out-of-pocket costs by up to $12,500 per calendar year.

‡Terms and conditions apply. See full Terms and Conditions at **Octagam10CoPay.com**

Pfizer IGuide™ is committed to providing access solutions for patients prescribed OCTAGAM 10%.

Call 1-844-448-4337, Monday through Friday, 8 AM to 8 PM ET, or visit www.PfizerIGuide.com

Common side effects include headache, fever, nausea, vomiting, increased blood pressure, chills, musculoskeletal pain, dyspnea, infusion site reactions, and increased heart rate.

If you use a blood glucose monitor, check with your HCP to ensure that your monitor and test strips are acceptable to use while you are receiving OCTAGAM 10%.

These are not all of the possible side effects with OCTAGAM 10%. Tell your HCPs about any side effects that you have that cause concern or don't go away.

Talk to your doctor or visit OctagamInfo.com to learn more

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the U.S. Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

Please see Brief Summary of full Prescribing Information on following page and full Prescribing Information, including complete BOXED WARNING, at OctagamInfo.com

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 PP-OTG-USA-0396 February 2025

octagam® 10%

Immune GlobuLin
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CONSUMER BRIEF SUMMARY

This brief summary highlights the most important information about OCTAGAM 10%. Please read it carefully before receiving OCTAGAM 10% and each time you have an infusion, as there may be new information. This brief summary does not take the place of talking with your healthcare provider (HCP) about your medical condition or your treatment. If you have any questions after reading this, ask your HCP. For more information, go to OctagamInfo.com/Octagam-10.

What is OCTAGAM 10%?

OCTAGAM 10% is a liquid medication that contains Immunoglobulin G (IgG). OCTAGAM 10% is used to treat chronic immune thrombocytopenic purpura (cITP) in adults and dermatomyositis (DM) in adults.

OCTAGAM 10% is made from human plasma donated by healthy people. For patients with cITP, it is used to rapidly increase the platelet count in the blood to help control or prevent bleeding. For patients with DM, it helps improve muscle function and skin rash.

OCTAGAM 10% is given through the vein (intravenously) in a hospital, infusion center, or at home by a trained HCP.

WARNING: THROMBOSIS, RENAL DYSFUNCTION, AND ACUTE RENAL FAILURE

- **Thrombosis may occur with immune globulin intravenous (IgIV) products, including OCTAGAM 10% liquid. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling central vascular catheters, hyperviscosity, and cardiovascular risk factors. Thrombosis may occur in the absence of known risk factors.**
- **Renal dysfunction, acute renal failure, osmotic nephrosis, and death may occur in predisposed patients who receive IgIV products, including OCTAGAM 10% liquid. Patients predisposed to renal dysfunction include those with a degree of pre-existing renal insufficiency, diabetes mellitus, age greater than 65, volume depletion, sepsis, paraproteinemia, or patients receiving known nephrotoxic drugs. Renal dysfunction and acute renal failure occur more commonly in patients receiving IgIV products containing sucrose. OCTAGAM 10% liquid does not contain sucrose.**
- **For patients at risk of thrombosis, renal dysfunction, or acute renal failure, administer OCTAGAM 10% liquid 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.**

Who should NOT use OCTAGAM 10%?

Tell your HCP if you:

- Have had a severe allergic reaction to IgG or other blood products
- Have deficiencies of immunoglobulin A (IgA) with antibodies to IgA

What should I know before receiving OCTAGAM 10%?

OCTAGAM 10% can cause the following:

- Blood clots in your heart, brain, lungs or other areas of your body
- Kidney problems, or kidney failure
- Tell your HCP if you have an allergy to corn. OCTAGAM 10% contains a type of sugar that is made from corn.
- If you use a blood glucose monitor, check with your HCP to ensure that your monitor and test strips are acceptable to use while you are receiving OCTAGAM 10%

OCTAGAM 10% can cause the following serious side effects. Contact your HCP if you experience the following:

- Swelling in your mouth or throat, hives/itching, breathing problems, wheezing, fainting, tightness in your chest, or dizziness. This could be a serious allergic reaction.
- Decreased urination, swelling in your legs, sudden weight gain, or breathing problems, which could mean kidney failure.
- Pain and/or swelling of an arm or leg with warmth in the affected area, discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens with deep breathing, unexplained rapid pulse, or numbness or weakness on one side of the body; these could be signs of a blood clot.
- Yellow skin or eyes, dark-colored urine, fatigue, or increased heart rate, which could be signs of a blood problem.
- Headache, stiff neck, drowsiness, fever, sensitivity to light, painful eye movements, or nausea and vomiting, which could mean an inflammation of the membranes covering your brain or spinal cord.
- Trouble breathing, chest pain, blue lips, arms or legs, and fever, which could be related to a lung problem. This typically occurs 1 to 6 hours following infusion.

What are the possible or reasonably likely side effects of OCTAGAM 10%?

Common side effects include headache, fever, nausea, vomiting, increased blood pressure, chills, musculoskeletal pain, dyspnea, infusion site reactions, and increased heart rate.

These are not all the possible side effects with OCTAGAM 10%. Tell your HCP about any side effects that you have that cause concern or do not go away. If you encounter any problems or experience side effects during or after the infusion, contact your HCP. When doing so, keep your therapy tracker with you to be able to give all necessary information.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

This brief summary is based on the OCTAGAM 10% Prescribing Information (March 2022).

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• *Food thermometer*: This is a must-have for any home chef. A thermometer helps make sure meats, seafood and mixed dishes are cooked properly and have reached a safe temperature. If your budget allows, you can also look for thermometers that have a probe that remains in the food during the cooking process. These probes automatically beep when food reaches the proper temperature, which means you don't have to move dishes in and out of the oven multiple times to check the temperature.

• *Oven gloves*: Traditional oven mitts can be bulky, making it difficult to properly grip a dish, especially if hand mobility or grip strength is a concern. Oven gloves are an alternative that fit much like a winter glove instead of the traditional mitten shape. They are heat-resistant, and also have a silicone coating on the outside to provide extra grip. They can also be used for other heat-related activities such as grilling, using a fireplace or handling hot pots or pan handles.

• *Immersion blender*: Immersion blenders are hand-held devices equipped with a blade at the bottom of a shaft. They are used to blend ingredients right inside a bowl or a pot (instead of transferring the food to a blender). They are great for blending soups, sauces and even smoothies, and may be easier to use and less cumbersome than a traditional blender or food processor.

• *Standing mixer*: Standing mixers are a great alternative to a hand mixer, especially for mixing batters and doughs. They can also be used to shred meats! They do require more counter space, which could be a consideration for those with a limited area to work with. They aren't for everyone, but they are ideal for those who love to bake.

• *Kitchen timer*: Symptoms like brain fog or fatigue can make certain cooking tasks more difficult. Using a kitchen timer, or the timer on a phone or smartwatch, can be especially helpful when these moments happen. Keep a timer somewhere visible to serve as a reminder to use it regularly.

Tips, Tricks and Recommendations

• *Capitalize on your good days.* Everyone has days when they have more energy than others. Make the most of those days by chopping a bunch of veggies, doubling a recipe or batch cooking staple items such as ground beef, beans or rice. That way, when you don't feel your best, you will have ingredients ready to put together for an easy meal.

• *Prep ahead of time.* It can be a lot to prep, cook and clean up three full meals every day. Recognize when you are most energized during the day, and try to prepare ahead of time for the moments when you have less energy to give. If you have more energy at night, use that time to get your breakfast ready for the next day. If you have more energy in the morning, set aside some time to prep the ingredients you need for dinner that night. Every little extra step ahead of time makes a big difference when your energy dips.

• *Use good lighting*. Make sure to keep the kitchen well-lit to prevent eye strain, accidents and fatigue. Cooler, brighter lights work better than warmer hues. Look for soft white light bulbs that mimic natural daylight to use in your kitchen.

• *Opt for shortcuts*. Every meal doesn't have to be made entirely from scratch. Don't be afraid to purchase and use pre-chopped, canned or frozen fruits and vegetables or pre-cooked grains and meats. These can make a big difference, especially on days when energy levels aren't their highest.

• *Invest in user-friendly brands*. The OXO brand of kitchen utensils originated after the founder's wife had trouble using a vegetable peeler due to her arthritis. Today, OXO offers a variety of utensils with a more comfortable and user-friendly grip for all, but they can be especially helpful for those with limited hand movement.

• *Electric salt and pepper mills.* If you like to season your food with freshly ground salt and pepper but find traditional cranking salt and pepper grinders tricky to maneuver, try going electric. Battery operated grinders are especially handy for people with limited hand strength.

• *Reorganize your kitchen*. Make your cooking space work for you by moving the items you use most often to an easy-to-reach spot. Having the items ready and available takes less effort and thought, which is especially important when you're not feeling your best. It takes a little extra energy upfront, but it will make kitchen tasks easier in the long run.

• *Look into food delivery services*. Grocery shopping can be a time- and energy-consuming task. Luckily, there are more and more food delivery options that do the hard work for you. These services can be especially helpful on the days when you're not feeling your best. Many offer discounts or promotions for first-time users as well. Some even offer to bring the groceries inside for you!

• *Give yourself grace*. Every day isn't going to be perfect. Embrace your highs and lows as they come. Give yourself the support you need at the moment. IG

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Diagnosing and Treating X-Linked Agammaglobulinemia

Affecting only males, XLA needs to be diagnosed early and requires lifelong immune globulin replacement therapy.

By Kathryn Smiley, PA-C, and Bob Geng, MD

X-LINKED AGAMMAGLOBULINEMIA (XLA) is a rare, inherited primary immunodeficiency (PI) that prevents the body from producing antibodies needed to fight infections. Affecting males due to its X-linked inheritance pattern, XLA is one of the earliest described primary immunodeficiencies. With timely diagnosis and proper treatment, individuals with XLA can lead full and healthy lives. This article overviews the epidemiology, clinical signs, diagnosis, treatment and emerging research for XLA patients, caregivers and healthcare providers.

Epidemiology and Genetics of XLA

XLA was first described by Ogden Bruton, MD, FAAP, in 1952, who recognized a male patient with recurrent infections and no measurable immunoglobulin G (IgG).[1] It is rare and occurs in approximately one in 100,000 to 200,000 live births. XLA is caused by a mutation in the Bruton's tyrosine kinase (BTK) gene that impairs signalling necessary for B-cell maturation and results in near-complete absence of functional antibody-producing cells (B cells) and immunoglobulins. The disease affects only males due its X-linked inheritance pattern. Female carriers are usually asymptomatic, but can pass the gene to an offspring.[2,3]

Clinical Presentation of XLA

Patients with XLA usually appear healthy at birth due to protective maternal antibodies received from the placenta. These antibodies wane around six to nine months, at which time XLA patients typically start to show symptoms. Patients commonly develop sinopulmonary infections, including recurrent ear infections, pneumonia and/or sinusitis. They can also develop severe infections as well, including sepsis or meningitis, typically from S. Pneumonia or H. influenza.[4] Other clinical features include poor vaccine response, which depends on antibody production, or recurrent skin or joint infections. Because XLA reduces all immunoglobulin levels, patients may have impaired mucosal immunity, leading to gastrointestinal symptoms such as diarrhea or malabsorption. These symptoms are often due to infections with organisms such as Giardia lamblia, Campylobacter jejuni or Salmonella species, or they may be related to autoimmune enteropathy.[5] Some patients are misdiagnosed with asthma or allergies before immunodeficiency is suspected.

Although female carriers of XLA are typically asymptomatic, studies have reported that some may exhibit mosaic or reduced BTK expression, as well as subtle immune abnormalities. These include reduced immunoglobulin levels, especially IgM, decreased vaccine titers or increased frequency of mild respiratory or autoimmune symptoms. Female carriers may also have skewed X-chromosome inactivation, which can unmask disease features more commonly seen in males.[6]

Diagnosing XLA

Clinical suspicion of XLA should arise in infants or young children with recurrent, severe bacterial infections. Diagnosing XLA relies on a combination of clinical suspicion, laboratory and genetic testing. Key diagnostic tests show profoundly decreased serum immunoglobulins (IgG, IgA and IgM), decreased or absent CD19+/CD20+ B cells and confirmatory genetic testing that shows

mutations in the BTK gene.[7] Poor or absent vaccine titers support the diagnosis. A differential diagnosis of other disorders that cause lack of or low immunoglobulins includes common variable immunodeficiency (CVID), severe combined immunodeficiency (SDID) and transient hypogammaglobulinemia of infancy.[8]

Treating XLA

XLA patients lack the ability to produce antibodies against disease-causing organisms. For this, lifelong treatment with immune globulin replacement therapy (IGRT) is the cornerstone in management.[1,8] There are two common routes of administration, intravenous immune globulin (IVIG) or subcutaneous IG (SCIG). IVIG is typically administered every three to four weeks either at home with home health nursing or in an infusion center. IVIG requires venous access, and infusion reactions, such as headache or chills, frequently occur.[9,10] SCIG is typically administered weekly or biweekly and can be administered at home by the patient, family or caregivers. There are typically fewer systemic side effects from SCIG, as well as more stable immunoglobulin levels over time.[10,11]

Both routes are effective and reduce infection rates, antibiotic use and hospitalizations. Dose adjustments are made based on patients' weight and clinical response, with IgG troughs typically greater than 500 mg/dL, but some patients may require higher IgG targets, especially those with chronic lung disease or frequent infections.[9,11]

SCIG is commonly preferred by patients for its convenience and independence, but route of administration is ultimately a shared decision between patients and providers. Additional recommendations include prompt use of antibiotics for breakthrough infections to avoid complications such as chronic lung disease (e.g., bronchiectasis). Some patients benefit from prophylactic antibiotic use. Live vaccines (MMR, varicella) are contraindicated due to the risk of vaccine-derived infections.[12] Inactive vaccines are not harmful, but they also are typically not effective. Other recommendations include routine IgG trough monitoring every three to six months and routine pulmonary function and/or imaging testing for lung surveillance.[2,8]

XLA Prognosis

With consistent treatment with IGRT, patients with XLA can lead full, active lives. Patients with XLA should avoid exposure to individuals with live viral infections. School, travel and participation in normal activities are possible with proper planning.

Emerging Research for XLA

Current research is being conducted to explore genetic therapies, individualized dosing and long-term outcomes. Preclinical studies using BTK gene insertion into hematopoietic stem cells show promise, though it is not yet available for clinical use.[10] Research is also being conducted to optimize IgG levels through pharmacokinetic modeling.[11] Real-world registry data is helping to evaluate infection rates, lung function outcomes and comparing IVIG vs. SCIG effectiveness.[12]

Key Takeaways

XLA is a lifelong PI requiring early diagnosis and continuous IGRT. An XLA diagnosis includes low IgG, IgA and IgM levels and absent B cells and confirmatory BTK gene mutation. IVIG and SCIG therapy are both effective, with the choice of administration dependent on a shared decision between patients and physicians based on a patient's age, lifestyle and preference. Research is evolving toward gene therapies and tailed dosing.

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Profile: Caitlin BenVau

By Trudie Mitschang

CAITLIN BENVAU is a talented rocket scientist whose work has taken her from the remote deserts of West Texas to the cutting-edge lunar landing projects in Cape Canaveral, Fla. Diagnosed at 13 with common variable immune deficiency (CVID), Caitlin's journey is a testament to resilience, community and the belief that health challenges don't have to define your future.

Trudie: Caitlin, your career path is fascinating. Can you tell us about your work as a rocket test engineer?

Caitlin: Yes! I lived in a remote Texas desert for five years testing rocket engines for a company planning to reduce the cost of access to space, specifically by launching large reusable rockets. My team's goal was to test the limits of the engines to ensure they could successfully handle the extreme launch conditions. Essentially, our role was to "trick" the engine into thinking it was flying by turning it on, or "hot firing" it, with all the same inputs and outputs it would have during flight. That includes cold cryogenic fluids, high-pressure flammable gases and dangerous voltages. Once the engine passed our tests, it was certified and the rocket was ready to be taken into space.

Trudie: How did you first learn you had CVID?

Caitlin: When I was 12 years old, I had a spider bite on my upper thigh that appeared normal. The next morning, the normal redness had spread into a terrifying radiating infection that was dark scarlet around the bite and red up to my torso and down to my knee. I found out it was necrotizing fasciitis, or flesh-eating bacteria. I had emergency surgery to remove the infection. But, doctors are trained to think of horses, not zebras, when they hear hooves, so they guessed I was bitten by a brown recluse and discharged me. Less than a few weeks later, I got a mosquito bite that rapidly began turning that dark red color again. Two back-to-back life-threatening infections raised some red flags, so they tested my immune system to discover I had extremely low IgG and IgA levels. I was finally diagnosed the week of my 13th birthday.

Trudie: What was treatment like in those early years?

Caitlin: My care team started me on the path to health with monthly intravenous immune globulin (IVIG) infusions in the cancer ward at Children's Hospital of Chicago. After that, I had a wonderful at-home nurse, Laura, who administered my IVIG through middle school. Partway through high school, we decided to try subcutaneous IG to give me more freedom when infusing, which especially helped out during engineering college.

Trudie: How has living with CVID shaped your outlook?

Caitlin: I've always seen my illness as core to my personal identity, but never my defining trait. I never let it hold me back. I was told it would be extremely difficult for someone with my illness to go to college, taking on stress and leaving my main support group. But, I really like challenges, so I saw it as an invitation to do something that was unexpected and would forge my own path in life. It's helped me to be more empathetic and warm to others, since I faced something that could have been very isolating in my formative years, but I wanted to keep being me.

Trudie: What first inspired you to pursue engineering?

Caitlin: As a kid, I was always very hands-on, building with Legos and Erector sets and ripping the heads off Barbies so I could see the ball joints that allowed their limbs to move. My interests were all over the place, but they always came back to a way I could test the limits of what I thought was possible and do something exciting. Mechanical engineering as a degree was attractive because it developed my hands-on skillset, and it helped me understand the physical world. Eventually, I developed a love for aerospace when I saw how the industry really challenged what was possible day after day.

Trudie: Have you had to adapt your work schedule, travel or assignments because of health?

Caitlin: Many times. In college, I worked with the student disability accommodations center to help with exam timing if I became sick, and I established good relationships with my professors. At work, there were times I needed to be remote when my medication wasn't available or it was caught up in insurance. And, I often had to use personal time off when I was sick rather than using it for vacations like most others. My honeymoon was the first time for me out of the country, and I made sure to get all appropriate vaccinations and prepare for the possibility of illness. I had a great time and did not get sick!

Trudie: How do you balance a demanding career with your health needs?

Caitlin: I have to be smart about my commitments. Balancing my go-getter personality with undeniable physical limitations has been an art form, certainly. I am a very hard worker and passionate about everything I do. When I become sick or fatigue catches up with me, I believe people see that it's not something I can control, and they don't criticize me for it. I make sure to be open with my team and my manager about my illness. They've been incredibly kind, from wearing masks in the office when they have a cold to helping out when I'm not as available.

Trudie: Tell us about your advocacy work.

Caitlin: I help out with many K-12 programs to get kids interested in STEM careers. But I also look for ways to inspire others dealing with health issues. At my company, I helped to start a resource group for employees facing mental and physical health challenges. We host internal social events, speakers and attend job fairs specifically for those with disabilities. It's important to me for others to know their voice matters and they have the support needed to succeed.

Trudie: What advice would you give companies that want to better support employees with invisible illnesses?

Caitlin: People are all over the comfort spectrum when dealing with an illness at work. Not everyone is as open as I am about their invisible illness, and they shouldn't have to be to get help. Providing training, specifically for managers, to teach them about available internal resources such as medical leave or remote work agreements is a great place to start.

Trudie: What does a typical infusion or treatment day look like for you now?

Caitlin: I'd compare it to a spa day, really! I typically infuse after work on Fridays, making sure to take the plasma out of the fridge early and warm it up. I premedicate and eat dinner beforehand, so I won't have to sit up. A lot of times my friends come over, or we virtually call to watch a movie and play video games together. Sometimes I sleep right through the whole process, and my husband, Florin, helps to swap out the medication. It takes around five hours for me to infuse, so it's good downtime from a busy schedule. I tend to go to sleep afterward and clean up the equipment the next day.

Trudie: What advice would you give young people with a primary immunodeficiency who are dreaming big?

Caitlin: Don't let your illness stop you. Medication is advancing every day, and it will only get better. It's important to understand yourself, respect your body and know your limits. Recognize that you are different, but that difference makes your life more meaningful and fun. Don't think of anything you do as "in spite of." You can do amazing things — such as living remotely, earning a tough degree and working in a demanding field — if you're smart about your health. In fact, I directly challenge you: Do something so cool that you make me excited, too!

Trudie: Looking back, what do you wish you had known at 13 when you were first diagnosed?

Caitlin: Not only was everything going to be OK in adulthood, but that I'd be able to have countless meaningful friendships and amazing life experiences, and I could handle an immune deficiency, too. It isn't an impossible task, and it isn't a death sentence. People really are kind-hearted and will understand. It would have been nice to know I wouldn't feel alone or different from the rest of the world. At the end of the day, I'm human, and there's nothing "wrong" with me. I'm so happy with how my life has turned out.

Trudie: How do you define success for yourself today?

Caitlin: I'm always pushing my boundaries as part of figuring them out. Success for me is recognizing when I need to take a break and then respecting that decision, which has been difficult. Ultimately, success is about being able to face a challenging day and be happy that I had the opportunity to do so. Days where I can wrap up a long project at work and still recognize I need to take a break and step back are when I feel successful.

TRUDIE MITSCHANG is a contributing writer for *IG Living* magazine.

Prior Authorization Blues

By Whitney L. Ward

EIGHT WEEKS. That's how long I went without my subcutaneous immune globulin treatment — the very thing that gives my body healthy B cells so my immune system can fight outside threats and flare-ups. My prescription had expired and my immunologist had left her public practice to open a private facility, so one of my other providers had to take over my treatment — and a prior authorization was needed.

This all led to the perfect storm: red tape, bureaucracy and medical insurance politics. With several back-and-forth phone calls among me, my doctor, the specialty pharmacy and the insurance company, the chaos didn't end for eight weeks. The frustrating part of this: If anyone was going to suffer from this ongoing battle, it would be me. Possible repercussions ranged from minor side effects such as inflammation and infections to serious side effects such as damage to my organs. Thankfully, I've only experienced sinus and ear infections and some fatigue. But this situation taught me a few things I want to pass on to you.

You must have tenacity! I know it can be exhausting. But, you must be tenacious with your extensive medical team, about taking all of your medications and treatments and making sure you have the accommodations you require to sustain your quality of life. And, if you need Social Security Disability income and Medicaid to pay for your expensive medical care, you must tenaciously make sure they have all the information they need to fix errors they made while processing your information. It's overwhelming, traumatic and exhausting when your body is already fighting hard to function. But here's what I had to keep reminding myself: Yes, juggling everything can be wearisome, but we must be the victors. Our stories show others what perseverance and never quitting looks like.

Get a teammate. As adults who are battling chronic illnesses, it's crucial we take ownership of our care because we know our bodies best and what we need to function. No one knows our story better than us. However, it's also crucial to have a support person for when we need help. Illness is unpredictable. Whether we're having a flare or we don't have time to be on the phone for hours, having help is essential.

I'm a teacher, and I work from 7:45 a.m. to 3:30 p.m. and then have a 35-minute drive home. By the time I get home, business hours are over for most facilities. The hours it took for my doctor and specialty pharmacy to coordinate what they needed from each other to appease my insurance company were too many for me to devote to while working. Thankfully, my mother's schedule allowed her to make these phone calls for me. Because she was listed as my emergency contact and I gave her my code word, the representatives and medical staff knew they could talk to her about my medical information. Without her willingness to help me, it would have taken much longer for me to receive my treatment. So, my advice to you: Don't feel like you have to do everything alone because you're the one battling disease. Find someone you trust to be your medical proxy who can advocate for you when you can't.

Being stern isn't being rude. After my doctor spent countless hours sending my specialty pharmacy what they were asking for, and my specialty pharmacy repeatedly claimed my provider's office wasn't sending the right information, the time came to be firm. Having a stern voice can sometimes be difficult and feel confrontational, but there are times when it becomes necessary.

The last representative I spoke to gave me the same spiel: "We still don't have what we need." And that's when I knew it was time to get stern. "Ma'am, I have to be honest: I'm frustrated. I know this isn't your fault and you're just giving me information, but I'm almost eight weeks late in taking my treatment and I'm starting to feel it. It's not fair to me because I'll be the one to suffer if I have to wait much longer. I've talked to you and my provider's office for hours and I still haven't gotten any answers."

It wasn't pleasant, but it got results: After sharing my frustration with this representative, I spoke to a pharmacist 10 minutes later who told me he had indeed received everything he needed, and insurance had approved my prescription and my treatment would arrive the next day. It can be exhausting to constantly have to be tenacious, accepting that you will sometimes have to depend on someone else, and to be bold enough to demand you receive the care you deserve, but remember what you're fighting for: to live your best life and give others hope. IG

WHITNEY L. WARD was not only the first person in the world diagnosed with MAGIS syndrome, but she also had the honor of naming the new primary immune deficiency. MAGIS means "more" in Latin, and Whitney hopes to instill in her readers the message they are more than their disease. Find out more about Whitney's journey at www.whitneylaneward.com.

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Home for the Holidays, Wherever That May Be

By Michelle Searle

GROWING UP in Florida, the holidays always looked a certain way: palm trees wrapped in twinkling lights, my grandmother's cooking on Christmas Eve and family gathered around the Christmas tree opening presents together with laughter. It wasn't cold or snowy, but it was ours. It was home. Now, "home for the holidays" looks a little different for several reasons. My grandmother is sadly no longer with us, my sister and I are not always in Florida for the holidays and we're living in a post-COVID world where it seems fewer and fewer people are getting vaccinated. I've spent the past few months living in Lisbon, Portugal, supporting college students who are studying abroad. Although I'm not staying through Christmas, I'm fortunate to experience the festive season as the city begins to glow. Twinkling lights are strung across the streets, storefronts are decorated with ribbons and garlands and Christmas markets pop up in plazas throughout the city. There's a festive warmth to it all. As I reflect on the places I've spent the holidays and the way they've changed, I'm reminded of what I've learned over the years: Home doesn't have to be tied to one location. It can be something you carry with you.

During my time in Italy, I experienced my first holiday season abroad, and it was during a pandemic, no less. That New Year's Eve, I stayed in with my then-boyfriend, now husband, and his mom. We ate delicious home-cooked food, watched *The Aristocats* in Italian, played Tombola, a classic Italian bingo-style game that's a staple during the holidays, and lit up sparklers. It was quiet, cozy and full of love. That New Year's Eve will always be one of my favorites. Ever since, playing Tombola has felt like a small way to bring that memory and feeling of connection into each new year.

This year in Portugal, I won't be staying for the actual holidays, but I'm soaking in the traditions all around me. In Lisbon, the scent of roasted chestnuts fills the streets, and there are sights of Bolo Rei, or King Cake, a round, fruit-studded sweet bread topped with candied fruit and powdered sugar, everywhere. I've found so much joy in watching the season unfold in a new setting. I see it in the sparkling lights lining Avenida da Liberdade. I hear it in the cheerful music at the markets. I feel it in the way people pause, just for a moment, to admire the decorations as they walk by. There's something comforting about knowing that no matter where we are in the world, people are finding ways to celebrate.

At the same time, I'm looking forward to being back in Florida for the holidays this year. After months of living abroad and adjusting to new routines, it will feel good to return to familiar surroundings. It will especially feel good to return to the heat! I'll spend time with family, watch Christmas movies, cook, bake and rest in the warmth of home.

If there's one thing I've learned about the holidays, it's that traditions evolve, and that doesn't make them any less meaningful. Over time, I've come to realize that the heart of the holidays isn't about doing things a certain way. It's about connection, comfort and moments that make us feel at home in our bodies and in our lives.

This year, I'm carrying a little bit of everything with me: a Lisbon December, a Florida Christmas and an Italian New Year's. I'm building something new from the places I've been, the people I love and the body I'm learning to listen to. If this is your year, and your body, life and energy allow it, go for it. Travel. Dress up. Bake something ambitious. Stay out later. Celebrate in the way that feels most you. Something our illness and the COVID pandemic have taught us is to be more present and not take these moments of connection and celebration for granted. If this isn't your year, that's OK, too. You're not missing out: You're taking care of yourself. There will be more holidays. More laughter. More cozy nights. You haven't run out of time. You're just honoring what you need to do right now.

If your holidays look different this year, whether because of illness, distance, grief or change, I hope you know you're not alone. You don't have to follow every tradition to have a meaningful season. You can create something uniquely your own. Home is not always a place. Sometimes, it's a feeling. And sometimes, it's a choice. This year, whatever your holidays look like, I hope you get to feel at home in your life, even just for a little while. IG

MICHELLE SEARLE is a teacher from South Florida who was diagnosed with common variable immunodeficiency at 11 years old. She is currently living in New York where you will most likely find her eating pizza or trying to make friends with the local cats.

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Teaching Kids the Difference Between Good Medicine and Harmful Drugs

By Jessica Leigh Johnson

CHILDREN WHO grow up with chronic illness are no strangers to medications. Taking prescription drugs is likely a part of a child's daily routine if he or she has been diagnosed with a primary immunodeficiency disease or other chronic illness. When taken according to a physician's instructions, prescription medications are helpful. But, many people abuse prescription drugs, and this can be confusing even for kids who have grown up taking medications. When kids grow older, they will likely encounter situations in which they need to make decisions about drugs, both good and bad, so it's vital they understand the difference between those that help them and those that can harm them.

Understanding What Drugs Really Are

The first step in teaching children about drugs is clarifying what the word "drug" means. A drug is a chemical that affects how the body or mind works.[1] Some drugs are used for healing and health, but even those drugs can be dangerous when used improperly or without medical supervision. Other drugs are never safe, and some are even illegal.

Parents can teach kids the difference between helpful and harmful drugs by placing them into categories. For example, medicines, such as the ones children take when they're sick or to prevent illness, are helpful drugs. These include antibiotics; cough syrups; allergy medications; creams and ointments for cuts, scrapes and bug bites; and pain relievers like ibuprofen and acetaminophen. Oftentimes, these medicines are prescribed by a doctor, and they are available to purchase at pharmacies.[1] These helpful drugs can become harmful, however, when they are not taken according to the package or doctor's instructions, or when they are taken when they are not needed. Parents should emphasize to their children the importance of following the doctor's instructions when taking any medication.

Legal drugs are another category of drug, and these include alcohol, nonmedical marijuana (in some states) and nicotine, which is found in cigarettes and e-cigarettes. Even though these drugs are legal for adults over 21 and can be purchased at stores, they are not prescribed by a doctor to treat or prevent illness, and they can cause serious health side effects.[1]

The last category is illegal drugs. When kids hear someone talk about a person who has a "drug problem," that person is likely abusing a legal drug or using an illegal drug such as ecstasy, crystal meth, cocaine, LSD or heroin to get high.[1] Illegal drugs are not safe for anyone, but they are especially dangerous for kids and teens because their bodies are still growing and developing. Many of these substances can lead to addiction, impaired judgment and, in some cases, death. Illegal drugs have the potential to damage vital organs such as the brain, heart, kidneys and liver. Cocaine can lead to heart attacks, even in children and teenagers.[1] What makes these drugs even more dangerous is that they may seem tempting, especially to teenagers, due to peer pressure, curiosity or unrealistic portrayals in movies or social media.

How and When to Start the Conversation

Experts at the University of Rochester School of Medicine suggest parents begin having conversations about drinking, smoking and drug use when children are between the ages of 5 and 7 years.[2] However, children can begin learning about helpful medicines at a very early age. From the moment they first take any kind of medication, they are learning about helpful drugs. Each time a child takes a medication, his or her parents can explain what the medicine is for and how it works to help the child's body to get healthy and/or stay healthy.

Parents can look for other teachable moments to open a conversation about nonmedical drug use. For example, if alcohol is served with a meal, it can be a good time to talk about drinking responsibly: how much is too much and what can happen to a person if too

much alcohol is consumed.[2] If a child sees someone smoking or drinking in a movie or on television, parents can use that opportunity to start a conversation about smoking, nicotine addiction and the effects of smoking on a person's lungs and overall health.[3]

Parents can also take their young children around the house and look at warning labels on everyday products. Even if they can't read, teach them to recognize warning symbols, such as the skull and crossbones symbol, which is often found on products that can be hazardous when inhaled or absorbed into the skin. It's also important to teach kids not to taste things they find around the house. Any harmful substance should be locked up or kept far out of reach of young children. Also important: Let young kids know medicine is not like candy. It might look or taste good, like a gummy vitamin or a fruit-flavored cough drop, but it still must be taken according to the package directions, just like any other medication.

As children start elementary and middle school, parents can refer to stories from real-life experiences or drug-related news stories such as drug use by someone in the public eye. When discussing real-life situations, parents should be sure their child understands what has happened, and the consequences of the drug use.[3]

Also at this age, the conversation can expand to include topics like peer pressure and refusal skills. By late elementary school, children should be equipped with simple, powerful ways to say no when offered something unsafe.[3] Parents can help with this by role-playing different scenarios so kids can practice. Here are three examples of simple refusal statements that kids can use if they are ever offered an unsafe substance:

- "No thanks, I don't want to take that."
- "I don't take anything unless my parent or doctor says it's OK."
- "I'd rather do something else."

It's important to make the home a safe space for kids to ask questions about drugs. Let them know there's nothing wrong with being curious. If kids hear something about drugs at school or on TV, they should feel free to talk it through with their family members. Parents can use a simple statement like, "If you ever see someone offering drugs or doing something unsafe, you can always tell me. You won't be in trouble. I just want you to be safe."

By the time children reach high school, they should be equipped with the skills to evaluate risk in every situation, think independently and make their own good choices, and then stand by those choices, even under pressure. Parents need to be aware that their teenage child may very well know kids who use alcohol or other drugs. Because of this, parents should be prepared to answer more specific questions about drugs.[3]

Teens will have already developed their own thoughts and feelings about drug-related issues such as drunk driving or vaping, so parents must be sure to talk about the real risks of drug use. For example, be clear that driving while intoxicated, whether by drugs or alcohol, is illegal, and a person who drives under the influence may go to jail or lose their license. Not only that, people who choose to drive while intoxicated could end up severely injuring or killing a pedestrian, passenger, someone in another vehicle or themselves.[3]

Parents of teens might want to consider making a written or verbal contract listing their family's rules and expectations when it comes to going out or using the car, being completely upfront about how the child is to behave in situations that involve drugs and/or alcohol. As part of the contract, have the child promise to call home if the driver of the car has been drinking or using drugs.[3]

It's also a good idea for parents of teens to stay up to date with drug street names and how different drugs affect the body, so they can give them accurate information if they ever have questions.[3]

Education Over Fear

Teaching kids the difference between helpful and harmful drugs isn't a one-time talk — it's an ongoing conversation. Parents should start early, give honest answers and keep the lines of communication open with their children. The goal of talking about drugs isn't to scare children into submission, but to give them the tools, confidence and understanding to make healthy decisions for themselves. When children learn the value of helpful medicines and the dangers of misusing drugs, they grow up empowered to make choices that protect their health and well-being. IG

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3. Better Health Channel. Talking to Kids About Drugs. Accessed at www.betterhealth.vic.gov.au/health/healthyliving/talking-to-children-about-drugs.

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.

First Aid at Home

By Rachel Maier, MS

MY KIDS SAY I am overprotective, but I think I am a responsible adult who hopes for the best, prepares for the worst and tells my still-growing kids "no" when something seems too risky. They are active and adventurous like their father, but accident-prone and clumsy like me, and they tend to get hurt during the course of regular life. Once, my son split open his scalp while playing with little toy cars on his low-to-the-ground, super-safe toddler bed. One of my daughters sustained a finger gash while using safety scissors at school. Both of my daughters collided while they were running on gravel in the dark, knocking each other to the ground and causing major knee injuries to both of them at the same time. I think insisting they wear helmets while learning how to use roller blades is fair and warranted, no matter how much they protest.

Clearly, despite my best efforts at keeping them safe, accidents still happen, and I have learned the value of keeping antiseptic, ointment and adhesive bandages close by. However, simple fixes aren't enough when injuries are more intense than a scraped knee. Sprained ankles benefit from ice packs and compression bandages; debris may need to be removed from wounds; bleeding may need to be controlled; allergic reactions need emergency medicine fast — the list of possibilities goes on!

First Aid Must Haves

You might be tempted to skip stocking up on first aid supplies since there is a chance you may never need the more specialized items often found in larger kits, such as a tourniquet or an emergency whistle. This phenomenon is called the "prophet's dilemma," which essentially means if you prepare for something, it won't happen. (Example: If I take an umbrella, it won't rain.) The good news is basic first aid kits aren't very expensive, and big box stores make it easy to purchase them. I keep one small, inexpensive kit in my car and a larger one in my storm shelter in the basement so I'm always equipped to respond to true emergencies; the smaller one cost about $10 and the larger one was about $30. For everyday use, I prefer to purchase the first aid supplies I use most often (antiseptic, bandages, ointment, etc.) individually and keep them stocked in an easy-to-reach kitchen cabinet.

What is best to buy? According to the American Red Cross, a well-stocked first aid kit should contain absorbent compress dressings, adhesive bandages, sterile gauze pads, adhesive cloth tape, antibiotic ointment, antiseptic wipes, aspirin, instant cold compress, nonlatex gloves, hydrocortisone ointment, roller bandage, oral thermometer, triangular bandages and tweezers.[1] Other items to consider keeping on hand include a breathing barrier with a one-way valve to use when giving CPR; epinephrine (injectable or nasal spray) for allergic emergencies; and naloxone to reverse the effects of an opioid overdose.

Be Prepared to Be Someone's Hero

Having a first aid kit you never use is better than facing a medical incident or emergency without the appropriate supplies. Preparing to respond to emergencies ahead of time will give you peace of mind and help keep you calm and focused if and when you need to provide first aid.

Again, your kit doesn't have to be fancy or expensive, and it doesn't need to include all the recommended supplies to be helpful in an emergency. As long as you have items that help you employ the three P's of first aid (preserve, prevent and promote), you will be ready to respond effectively:[2] Preserve life by assessing the victim's condition, including making sure their airway is clear and administering CPR if needed; prevent deterioration by stopping bleeding, immobilizing fractures and disinfecting and dressing wounds; and promote recovery by alleviating pain and keeping the individual comfortable until emergency services arrive, if they are needed and called.

You will be happy you have what you need to be able to do these tasks effectively and efficiently — and hopefully, you'll never need them at all.

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RACHEL MAIER, MS, is the associate editor of *IG Living* magazine.

American BLS Basic First Aid Skills Course

Do you know how to recognize a life-threatening situation and perform first aid on a victim? If not, consider taking this free course to learn the skills you need to save lives. The course goes over how to recognize many common emergencies, including choking, bleeding, poisoning, burns, allergic reactions and much more, and gives you the tools and information you need to properly respond to and treat each emergency. *Free; www.americanbls.com/courses/online-first-aid-course*

Welly Bandages

Who says adhesive bandages have to be boring? Welly makes fun, flexible fabric bandages that are as stylish as they are effective. Each bandage is sealed in a clear wrapper that keeps the bandage sterile and makes it easy to find the print, pattern and size you need in a pinch. This mighty 200-count pack comes with nine favorite patterns in three different sizes so there's a go-to for all kinds of minor cuts and scrapes. *$19.98; www.amazon.com/Welly-Adhesive-Flexible-Bandages-Assorted/dp/B0BW1KT4HP*

Shopping Guide for At-Home First Aid

FlexiKold Gel Soft Flexible Ice Packs by NatraCare

Instant cold packs are great on the go, but these reusable ice packs are fantastic for keeping in the freezer for at-home use. FlexiKold Gel Cold Packs deliver unmatched flexibility and longer-lasting cold therapy thanks to a proprietary gel formula. Unlike bentonite-based packs that turn stiff in the freezer, FlexiKold ice packs stay smooth and pliable, molding comfortably to any part of your body. Its gel holds the cold longer. Its thinner, more comfortable design maximizes skin contact for faster, more effective relief. *$12.99; natracure.com/collections/flexikold-gel-cold-packs/products/flexikold-gel-cold-pack-medium*

Band-Aid Antiseptic Spray

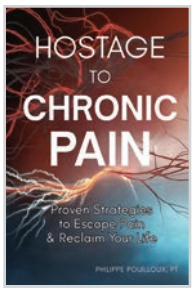
The perfect addition to an at-home first aid kit, this antiseptic cleansing spray helps clean and relieve pain of minor wounds, cuts, scrapes and burns. It contains the topical analgesic pramoxine HCl to help alleviate pain and discomfort from minor wounds and benzalkonium Cl, a first-aid antiseptic that can be used to effectively kill germs and help prevent infection. *$8.48; www.amazon.com/Band-Aid-Relieving-Antiseptic-Cleansing-Pramoxine/dp/B09N1R2WSS*

SafeSkin Nitrile Exam Gloves

These gloves offer barrier protection for low to moderate exposure to fluids — perfect for using when administering first aid. SafeSkin Medium Duty gloves are high-quality nitrile and are not made with natural rubber latex. They are powder-free and offer a comfortable fit and feel, and even have textured fingertips for better tactile sensitivity. And, they come in an easy-to-open POP-N-GO pack, which dispenses one glove at a time. *$9.99; www.amazon.com/SAFESKIN-Nitrile-Disposable-POP-N-GO-Powder-Free/dp/B091J51LX5*

General Medi First Aid Kit

Packed with 360 useful and valuable hospital-grade medical supplies, this ultimate first aid kit consists of everything that you need to clean and dress minor wounds. The box is made of high-density, waterproof plastic and can be mounted on a wall for quick access. This kit will give you the peace of mind you deserve for small trauma during every adventure at home, school, office and the outdoors. *$30.99; www.amazon.com/General-Medi-Pieces-Hardcase-First/dp/B0CJ9F7JRB*



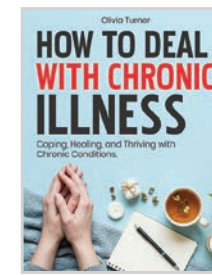
Hostage to Chronic Pain: Proven Strategies to Escape Pain & Reclaim Your Life

Author: Philippe Pouilloux, PT
Publisher: Independently published

Hostage to Chronic Pain is a compassionate, science-backed guide created specifically for those who have been dismissed, misdiagnosed and left to figure it out on their own. Inside, readers will discover powerful, practical tools to help relieve pain naturally with holistic, non-drug approaches; rewire your brain with neuroplastic techniques proven to reduce suffering; use mindfulness to shift your pain response and calm the nervous system; recognize when treatment is failing and learn what to do instead; build a support network that truly understands what you're going through; explain your pain to others in a way that finally helps them get it; and more. Readers will be inspired by real-life success stories from people who once felt stuck, hopeless and unheard until everything changed.

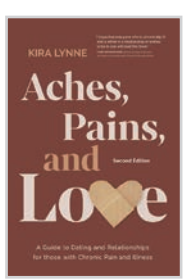
How to Deal with Chronic Illness: Coping, Healing, and Thriving with Chronic Conditions

Author: Olivia Turner
Publisher: Independently published



This book offers compassionate, practical guidance to help readers navigate the physical, emotional and mental challenges of chronic conditions. Included are proven coping strategies to manage symptoms and improve quality of life; mindfulness and stress-relief techniques tailored for chronic illness; tips for communicating effectively with healthcare providers and loved ones; lifestyle adjustments to support physical and emotional well-being; and encouragement and resilience-building exercises.

New and Useful Reading



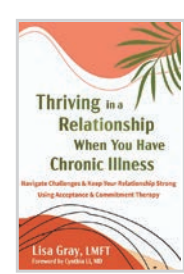
Aches, Pains, and Love: A Guide to Dating and Relationships for Those with Chronic Pain and Illness — Second Edition

Author: Kira Lynne
Publisher: Moppet Press

In the second edition of *Aches, Pains, and Love*, clinical counselor and chronic illness survivor Kira Lynne offers compassionate and practical guidance and wisdom for navigating relationships while living with significant health challenges. Whether contemplating dating or seeking to strengthen an existing partnership, this book provides real-life stories, practical observations and proven tools to help readers achieve the love they are longing for. Readers will discover how to approach dating with confidence, even when health challenges feel daunting; communicate effectively about their needs, limitations and boundaries; and support to grow their relationship through the ups and downs of chronic illness.

Thriving in a Relationship When You Have Chronic Illness: Navigate Challenges and Keep Your Relationship Strong Using Acceptance and Commitment Therapy

Authors: Lisa Gray, LMFT, and Cynthia Li, MD
Publisher: Tantor Media



Grounded in evidence-based acceptance and commitment therapy, this grief-informed guide offers powerful skills to help individuals and their partners adjust, communicate and protect their bond. Readers will learn positive coping strategies to help manage difficult emotions such as anger, sadness and grief; promote intimacy and understanding between themselves and their partners; and identify what it is that truly matters to both parties — to move forward in life with values closely aligned.

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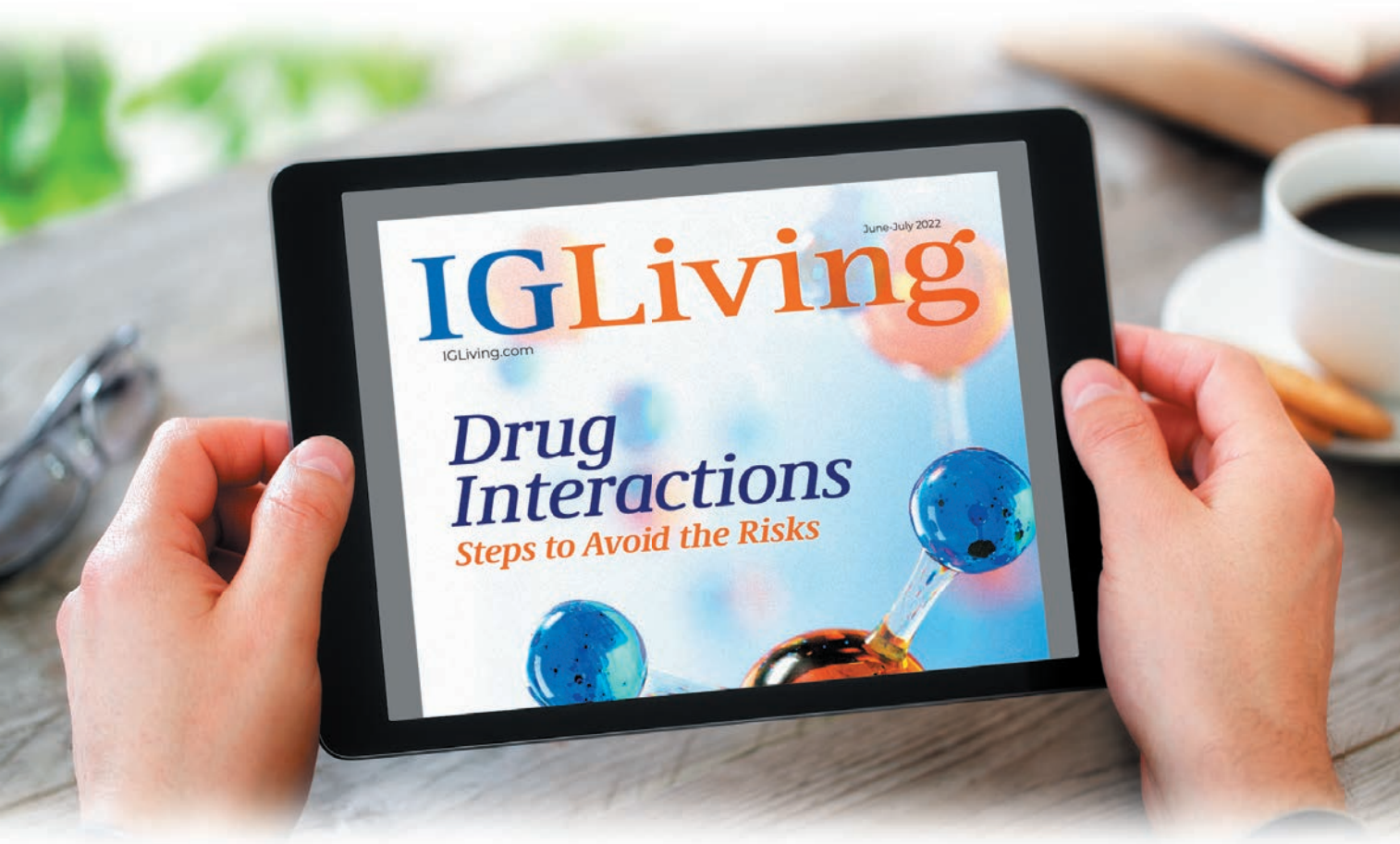

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Ataxia Telangiectasia (A-T)

Websites

- A-T Children's Project: www.atcp.org

Chronic Inflammatory Demyelinating-Polyneuropathy (CIDP)

Websites

- GBS/CIDP Foundation International: www.gbs-cidp.org

Evans Syndrome

Online Peer Support

- Rare Connect Evans Syndrome Community Group: www.rareconnect.org/en/community/evans-syndrome/faqs

Guillain-Barré Syndrome (GBS)

Websites

- GBS/CIDP Foundation International: www.gbs-cidp.org
- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Online Peer Support

- GBS Support Group: www.gaincharity.org.uk
- GBS/CIDP Foundation International Community Forums: forum.gbs-cidp.org

Immune Thrombocytopenia (ITP)

Websites

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

Kawasaki Disease

Websites

- American Heart Association: www.heart.org/en/health-topics/kawasaki-disease
- American Academy of Family Physicians: www.aafp.org/afp/2006/1001/p1141.html
- Kawasaki Disease Foundation: www.kdfoundation.org
- KidsHealth: www.kidshealth.org/parent/medical/heart/kawasaki.html

Mitochondrial Disease

Websites

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

Multifocal Motor Neuropathy (MMN)

Websites

- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Multiple Sclerosis (MS)

Websites

- Multiple Sclerosis Association of America: www.mymsaa.org
- Multiple Sclerosis Foundation: www.msfocus.org
- National Multiple Sclerosis Society: www.nationalmssociety.org

Online Peer Support

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

Myasthenia Gravis (MG)

Websites and Chat Rooms

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

Online Peer Support

- Genetic Alliance: www.geneticalliance.org

Myositis

Websites

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

Online Peer Support

- Juvenile Myositis Family Support Network: www.curejm.org/fsn/index.php
- The Cure JM Foundation: www.curejm.org
- Myositis Association Support Group: www.myositis.org/patient-support/support-groups
- Myositis Support Group – UK: www.myositis.org.uk

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)

Websites

- PANS/PANDAS UK: www.panspandasuk.org
- PANDAS Network: www.pandasnetwork.org
- PANDAS Physician Network Family Resources: www.pandasppn.org/parent-information
- National Institute of Mental Health: www.nimh.nih.gov/health/publications/pandas/index.shtml

Pemphigus and Pemphigoid

Websites

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

Peripheral Neuropathy (PN)

Websites

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

Primary Immune Deficiency Disease (PI)

Websites

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

Online Peer Support

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

Scleroderma

Websites

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

Online Peer Support

- Scleroderma Support Forum: www.curezone.com/forums/f.asp?=404

Stiff Person Syndrome (SPS)

Websites

- American Autoimmune Related Diseases Association Inc.: www.aarda.org
- Genetic Alliance: www.geneticalliance.org
- Living with Stiff Person Syndrome (personal account): www.livingwithsps.com
- The Stiff Person Syndrome Research Foundation: stiffperson.org

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