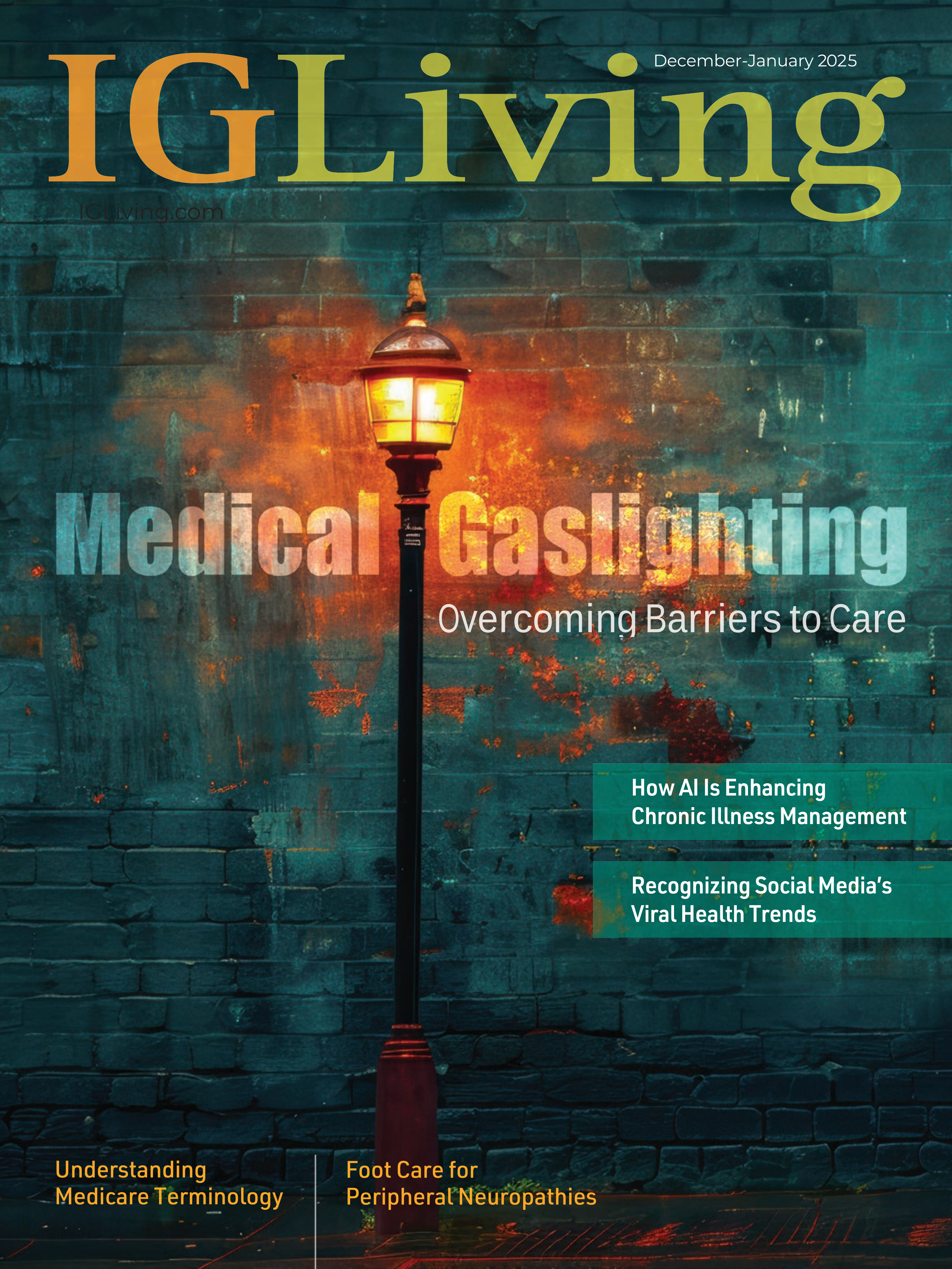
IGLiving

December-January 2025

IGLiving.com



Medical Gaslighting

Overcoming Barriers to Care

How AI Is Enhancing Chronic Illness Management

Recognizing Social Media's Viral Health Trends

Understanding Medicare Terminology

Foot Care for Peripheral Neuropathies

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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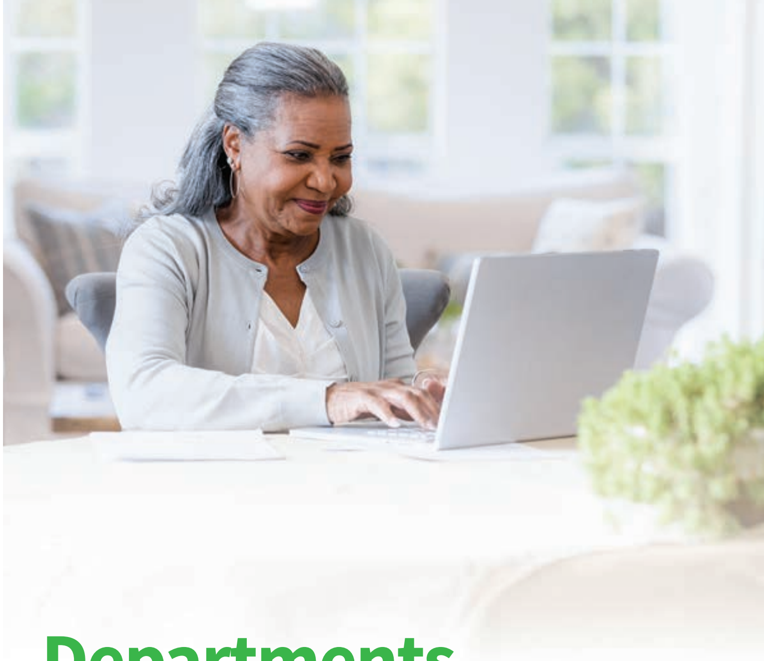

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Advertising in IG Living
IG Living Magazine is read by 30,000 subscribers who are patients that depend upon immune globulin products and their healthcare providers. For information about advertising in IG Living, download a media kit at igliving.com/advertise/advertise.html. Or contact advertising@igliving.com.

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

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From the Editor

Examining Issues in Managing Chronic Illness

THERE ARE many reasons it takes so long for those in the primary immunodeficiency and autoimmune disorder communities to receive a diagnosis. Vague and overlapping symptoms can make it difficult to discern one disease from another, and a lack of awareness among healthcare providers about immune system disorders and what to look for is common. These are understandable, and the latter is receiving more attention in recent years. What's not understandable and what continues to receive inadequate attention and discussion is medical gaslighting.

Medical gaslighting is a troubling phenomenon in healthcare that occurs when patients' concerns are minimized or ignored, and potentially leads to misdiagnosis and delayed treatment. The term has been around since the 19th century when women's complaints about their health were often referred to as "female hysteria," but even though that is now recognized as gender bias, the practice persists today. Unfortunately, as we highlight in our article "Medical Gaslighting: A Growing Concern in Modern Healthcare" (p.24), gaslighting happens much more frequently with women, and the physical and psychological toll it takes on patients is not only mentally traumatizing but it results in severe consequences to their health. So, we provide some expert-recommended solutions for both the practitioner and patient communities to help change the trajectory of this harmful practice.

Could artificial intelligence (AI) be one potential solution to medical gaslighting? After all, it's difficult to refute someone's symptoms when smart devices are tracking them, proving they are all too real. What's more, AI can warn physicians of health issues that could potentially become more serious. We explain the myriad benefits of AI in our article "Smart Health: How AI Is Shaping the Future of Chronic Illness Management" (p.28), as well as look at the challenges it still poses. However AI is used, it's clear that it is the future of chronic disease management.

Digital technology has made amazing strides in healthcare, especially when it comes to social media. But, as much as we look to technology for medical advice, we should all be wary of everything we read. In our article "Too Bizarre to Be True: Social Media's Viral (and Hazardous) Health Trends" (p.36), we recognize the benefits of social media for both patients and providers, but we also provide some examples of the outlandish health trends that, while they might *seem* to offer health benefits, can also be extremely harmful.

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.

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National Health Information Awards Winner 2021
MarCom Awards

When to Sign Up for Medicare if You're Still Working at 65 and Beyond

By Abbie Cornett, MBA

WHILE WRITING an article about Medicare for this issue of *IG Living* (p.44), it occurred to me that, like many other people who are still a few years away from being eligible for Medicare, I have no plans to stop working when I turn 65. If you are in this demographic and are still employed and have employer-sponsored insurance, you may be wondering when the best time is to enroll in Medicare. Knowing how the enrollment process works when you're still on the job can help you to avoid penalties and make sure you're getting the most out of your coverage.

Medicare Part A. Many people choose to enroll in Medicare Part A at age 65, even if they delay enrolling in Part B, since it helps cover hospital stays, skilled nursing facility care, hospice care and home healthcare, and it won't interfere with employer-provided coverage.[1] However, if you contribute to a health savings account (HSA), enrolling in Part A can impact your ability to make further contributions. Medicare Part A is typically premium-free for most people, especially if you've worked for at least 10 years and paid Medicare taxes.

Employer insurance vs. Medicare Part B. Employer insurance and Medicare Part B can work together for individuals eligible for both. Employer-provided insurance typically includes medical and sometimes dental or vision coverage. On the other hand, Medicare Part B covers outpatient services such as doctor visits, preventive care and durable medical equipment. When coordinating the two, it's crucial to understand how employer insurance interacts with Medicare. If your employer's insurance qualifies as "creditable coverage," you can delay Medicare Part B enrollment without penalties.[2] Medicare Part B has a premium and may duplicate some of your employer coverage, so it's essential to weigh the costs and benefits before enrolling in Part B.

Size matters. It's important to note that the size of the company providing your insurance plays a significant role. Companies with 19 or fewer employees can require you to enroll in Medicare Parts A and B when you turn 65 to maintain your employer coverage. If you don't sign up for Medicare, you could experience a gap in your health coverage. However, companies with 20 or more employees are required to continue offering health insurance to workers and their spouses who are 65 or older. If you're covered under a plan in a company of that size, you have the option to enroll in Medicare and decline your group plan, but your employer cannot force you to make this decision.[3]

Special enrollment period. For those still working, you can delay Medicare Part B and use your employer-provided insurance as your primary health coverage. When you retire or lose employer coverage, a special enrollment period (SEP) allows you to enroll in Medicare Part B without facing late enrollment penalties. This SEP lasts for eight months after your employment coverage ends, making it important to plan the timing of your enrollment to avoid a gap in healthcare coverage.[2]

Prescription drug coverage and employer insurance. Medicare Parts A and B do not generally cover prescription medications taken at home. If your employer insurance includes prescription drug coverage, this may allow you to delay enrolling in Medicare Part D. Medicare Advantage plans, which offer additional benefits like prescription drug coverage, may also be an option to consider if you're thinking of leaving employer coverage.

Coordination of benefits. When keeping both employer coverage and Medicare, the two plans will coordinate benefits. Typically, if your employer has 20 or more employees, your employer insurance is the primary payer, while Medicare serves as secondary coverage. If your employer plan is secondary, Medicare pays first, and the employer plan covers remaining costs, ensuring you maximize your coverage. When enrolling in Medicare, individuals must complete the initial enrollment questionnaire (IEQ) through MyMedicare.gov to inform Medicare of any other insurance, which helps determine how benefits are coordinated.[4] IG

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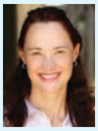

ABBIE CORNETT, MBA, is the patient advocate for *IG Living* magazine. She can be reached at patientadvocate@igliving.com or (800) 843-7477 x1366.

How Do You Survive Health Advice on Social Media?

If I find something that I think may possibly be helpful, which is a super rare occurrence, I discuss it with my doctor(s).

Unless it is from a valid, verified source, I delete it.

Like others, I completely ignore health advice on social media, no matter who the advice-giver claims to be. For liability reasons, most medical professionals will never give out advice online to someone who isn't their patient, so if someone comes onto a social media site giving out advice, I immediately doubt their credentials and integrity. And when people start aggressively pushing specific meds, supplements or treatments, I usually assume they are getting kickbacks from those products.

I ignore most if not all health advice on social media. I trust that my immunologist and other physicians will give me the best information for me.

How Do You Stay Socially Active with PI?

I walk with friends almost every day, text and FaceTime with long-distance friends and family, and volunteer when it's a good fit for me.

My social circle has shrunk since being diagnosed. There are only so many times you still get invited when you've cancelled at short notice before. I've a lovely few friends now and have to decide on a daily basis whether I socialize or not. I spend a lot of time at home, some of it alone, to avoid infections.

I'm largely home-bound, so I keep in contact with my friends through text or Facebook messenger.

It's a lonesome road to travel, and people really don't understand that!

Actually, I only really have one friend and she has a ton of health conditions. She works from home so I talk with her on the phone on weekends. She doesn't have a smartphone so I can't FaceTime with her, and my mom lives in Arizona and she has a ton of health problems, so I talk with her on the phone. I'm not socially active at all. I am basically home other than if I go to a grocery store once a week or every other week, or if I go to the hospital for tests and doctor appointments. I have multiple health conditions, and I haven't worked since 2007. Most people my age are grandparents with three to 10 grandkids at this point, or their kids are getting to be 30- to 35-year-olds and are getting married now. I'm single, no kids, so I'm in a completely different dynamic.

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.

HyQvia

[Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase]

10 **Trusted by doctors treating people with PI for over a decade***

*Initial FDA approval for PI: 2014.

Cheryl and 3,000+ people each year† have treated their PI with the **only once-monthly‡ subQ IG therapy**

‡Every 3 to 4 weeks.

Cheryl's doctor determined HyQvia was the appropriate therapy for her PI. Please note that she does not represent all patient experiences.

†Over the last decade. Data based on Takeda Primary Demand Dataset, January 2015–May 2024.
PI=primary immunodeficiency; subQ IG=subcutaneous immune globulin.

What is HyQvia®?

HyQvia [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] is a liquid medicine that is given under the skin (subcutaneously) to treat primary immunodeficiency (PI) in people 2 years and older.

IMPORTANT SAFETY INFORMATION

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

- HyQvia can cause blood clots.
- Call your healthcare professional (HCP) if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your HCP may perform blood tests regularly to check your IgG level.
- Do not infuse HyQvia into or around an infected or red swollen area because it can cause infection to spread.

Please see additional Important Safety Information on next page.

HyQvia is a subQ IG therapy infused monthly,[‡] or up to every 28 days apart. That gives every person on HyQvia more time between infusions—unlike other subQ IG therapies, where weekly or even daily infusions are necessary. So here's to people living with PI we will continue to help with the only once-a-month[‡] subQ IG infusion.

[‡]Every 3 to 4 weeks.

Interested in learning more about HyQvia from Cheryl and other patients like her? Register for a community educational program created for people living with PI—MyLifeMyStory.com. And for more information, visit HyQvia.com.

IMPORTANT SAFETY INFORMATION (continued)

Who should not take HyQvia?

Do not take HyQvia if you:

- Are allergic to IgG, hyaluronidase, other blood products, or any ingredient in HyQvia.

What should I avoid while taking HyQvia?

- HyQvia 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 HyQvia.

What should I tell my HCP before I start using or while using HyQvia?

Tell your HCP if you:

- Have or had any kidney, liver, or heart problems or history of blood clots because HyQvia can make these problems worse.
- Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products.
- Are pregnant, trying to become pregnant or are breast feeding. It is not known whether HyQvia can harm the unborn baby or breastfed infant.

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

HyQvia can cause serious side effects. If any of the following problems occur after starting HyQvia, 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, other than at the infusion site(s). These could be signs of a blood clot.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.
- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a serious heart or lung problem.
- Fever over 100°F. This could be a sign of an infection.

After HyQvia infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused. The following possible side effects may occur at the site of infusion and generally go away within a few hours, and are less likely after the first few infusions.

- Mild or moderate pain
- Redness
- Swelling
- Itching

The most common side effects of HyQvia are:

- Headache
- Fatigue
- Nausea
- Fever
- Vomiting

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

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.

Please see Important Facts about HyQvia on the following page.

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

Takeda

IMPORTANT FACTS about HYQVIA (Hi-Q-via) [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] Solution, for subcutaneous administration

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

- HYQVIA can cause blood clots.
- Call your healthcare provider (HCP) if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your HCP may perform blood tests regularly to check your IgG level.
- Do not infuse HYQVIA into or around an infected or red swollen area because it can cause infection to spread.

What is HYQVIA?

HYQVIA is a liquid medicine containing immune globulin and Recombinant Human Hyaluronidase. HYQVIA is given under the skin (subcutaneously) to treat primary immunodeficiency (PI) in people 2 years of age and older. HYQVIA contains IgG antibodies, collected from human plasma donated by healthy people.

- The antibodies help your body to fight off bacterial and viral infections.
- The hyaluronidase is found in your body naturally. It's the first part of your two-part infusion. It temporarily opens the space under your skin (the subcutaneous space), allowing a larger amount of IgG to reach your subcutaneous tissue and be absorbed into your bloodstream.

What should I tell my HCP before I start using or while using HYQVIA?

Tell your HCP if you:

- Have or had any kidney, liver, or heart problems or history of blood clots because HYQVIA can make these problems worse.
- Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products.
- Are pregnant, trying to become pregnant, or are breastfeeding. It is not known whether HYQVIA can harm the unborn baby or breastfed infant.

Who should not take HYQVIA?

- Do not take HYQVIA if you are allergic to IgG, hyaluronidase, other blood products, or any ingredient in HYQVIA.

How should I take HYQVIA?

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

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

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

The following local reactions may occur at the site of infusion and generally go away in a few hours. Local reactions are less likely after the first few infusions.

- Mild or moderate pain
- Redness
- Swelling
- Itching

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

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

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

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

These are not all of the possible side effects for HYQVIA. You can ask your HCP for information that is provided to HCPs. Talk to your HCP about any side effects that bother you or that don't go away.

How do I store HYQVIA?

Store HYQVIA refrigerated or at room temperature.

- You can store HYQVIA in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 36 months.
- You can store HYQVIA at room temperature (up to 77°F [25°C]) for up to 3 months during the first 24 months from the date of manufacturing (Mfg Date) printed on the carton.
- Do not return HYQVIA to the refrigerator if you take it out to room temperature.

Check the expiration date on the carton and vial label. Do not use HYQVIA after the expiration date.

Do not freeze.

Protect from light. You can use the original HYQVIA containers to protect it from light.

How do I get more information about HYQVIA?

The risk information provided here is not comprehensive. To learn more, talk about HYQVIA with your HCP or pharmacist. The FDA-approved Full Prescribing Information, including Information for Patients, can be found at www.HYQVIA.com or by calling 1-877-TAKEDA7 (1-877-825-3327).

Patented: please see https://www.takeda.com/en-us/patents/

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How Can I Connect with Other CIDP Patients?

I've recently been diagnosed with chronic inflammatory demyelinating polyneuropathy (CIDP), and I'm feeling overwhelmed and isolated. How can I find and connect with other patients who are experiencing similar challenges so I don't feel so alone?

Abbie: When managing a chronic illness like CIDP, connecting with others who truly understand your experiences can be incredibly beneficial. One of the most effective ways to find support is by joining online communities such as forums, social media groups or websites specifically for CIDP or chronic illness patients. We invite you to visit our Facebook page (www.facebook.com/IGLivingMagazine) where we focus on the challenges faced by those with chronic illnesses and regularly share information on specific conditions such as CIDP.

These platforms provide a space to share your journey, ask questions and offer mutual support, helping you feel less isolated. Additionally, you might consider connecting with local or national organizations that focus on CIDP or similar conditions. These groups often organize events, webinars and support groups where you can connect with others, either in person or virtually.

Remember that a diagnosis of a chronic illness can feel isolating, but there are resources available to help. If you're feeling alone, don't hesitate to reach out to your healthcare provider for recommendations on local support groups or counseling services. They can often connect you with resources specifically tailored to your needs. You're not alone in this journey. By actively seeking out these connections, you can find a community that offers understanding, encouragement and a shared sense of resilience. At IG Living, our purpose is to help patients navigate their challenges and find the support they need.

How Do I Deal with Hard Knots Forming Under My Skin When Infusing SCIG?

I infuse 10 grams of immune globulin (IG) subcutaneously every seven days over two hours. I have formed hard knots under my skin in so many infusion sites that it is getting difficult to find sites to infuse. I rotate thighs and belly where I can find areas not already knotted up. If I do place a needle in areas with knots, it will not infuse. Is there a solution to this?

Abbie: I spoke with Michelle Greer, RN, IgCN, executive vice president of sales at Nufactor, a specialty infusion company, and she said the formation of hard knots under the skin at infusion sites is a common issue with subcutaneous IG therapy, which can be frustrating when it limits your available infusion sites. Here are some strategies that might help:

1) Warm compresses: Before and after infusions, apply a warm compress to the area. This can help increase blood flow, soften the tissue and make it easier to infuse.
2) Massage: Gently massaging the area where the knots have formed may help break them down over time. Be careful to avoid excessive pressure, which could cause more irritation.
3) Site rotation: Continue rotating your infusion sites as much as possible. Even though you're already doing this, try to map out your sites more precisely, ensuring you're giving each area adequate time to heal before infusing in that site again.
4) Smaller volumes, more frequent infusions: Talk to your healthcare provider about possibly infusing smaller amounts more frequently. This can reduce the load on each infusion site, giving your skin more time to recover.
5) Needle placement and depth: Consider requesting a nursing visit to ensure you're using the correct technique and needle length for your height and weight. Proper placement can make a big difference in reducing these issues.
6) 20% solution: Ask your healthcare provider or specialty pharmacy if you can switch to a 20% IG solution. This higher concentration would mean less volume to infuse, which could simplify your infusions and potentially reduce site reactions.
7) Contact your specialty pharmacy: It's also a good idea to reach out to your specialty pharmacy for assistance, which can help ensure you have the best supplies and techniques for your infusions.

Before doing anything, please remember the importance of speaking with your healthcare provider before making any changes.

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

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Embracing a New Year with *No Resolutions*

By Mairead McConnell, PhD

AS THIS YEAR comes to a close and we prepare for the dawn of 2025, we will undoubtedly encounter conversations, advertisements and pressure to make a resolution for the new year. While resolutions can be an exciting and hopeful way to embrace a new season, more often than not, resolutions are aspirational, unrealistic and unlikely to be achieved. Resolutions can set us up for disappointment and are a way of sending ourselves the message that who we are today is not good enough.

> While resolutions can be an exciting and hopeful way to embrace a new season, more often than not, resolutions are aspirational, unrealistic and unlikely to be achieved.

You Are Already Enough

No matter where you are in your life, how near or far you are from reaching your goals or being the person you want to be, there is always room for growth. While this is true, it is also true that who you are today — exactly as you are today — is already a person worthy of love, respect and good things. As you prepare for this new year, take a moment to consider all that 2024 was for you, instead of focusing on what it lacked. Every season of life has a purpose. Consider the lessons you learned; take time to focus on the strengths and qualities you already embody today.

Intentions Over Resolutions

The word "resolution" implies that something will be fixed, once and for all. In reality, change doesn't work this way. Real change happens one day, one step at a time, not all at once or overnight. Intentions can be used for self-reflection and to help identify the direction you want to move. Consider these tips for successfully setting and living aligned with your intentions:

- *Focus on the how and why.* Intentions are different from resolutions or goals; they are not something you can check off a list. Intentions are less about what you do and more about how and why you do what you do. Consider how you want to show up this year — for yourself, your health, your relationships, your life? What guiding principles and values do you want to keep in mind? When we set intentions that are aligned with our values, we are less likely to abandon them after a few weeks, and honestly, you can't fail. Intentions are not about achieving some end result; they are about showing up each day in a way that aligns with who you want to be.
- *Move toward what you want.* Many people make the mistake of setting intentions or goals that are about restriction such as "I want to use my phone less" or "I want to eat less sugar." Instead, focus on moving in the direction of what you do want. Maybe it is more time in nature, more connection with community or a deeper understanding of yourself. Researchers refer to these as "approach-oriented" goals, and evidence shows that this framing is ultimately more effective and beneficial than avoidance.[1]
- *Start with today.* There's no need to wait for a new month or year to start living aligned with your values. Today is as good a day as any. As you embark on this journey, don't worry about whether you will be able to keep this up all year. Life unfolds one day at a time, so give yourself the grace to live it that way. If (and when) you lose sight of your intention, simply take a deep breath, gently remind yourself and keep going.

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SARS-CoV-2 and COVID-19: Autoimmunity

By Terry O. Harville, MD, PhD

PREVIOUSLY, WE discussed that the immune system has not co-evolved with SARS-CoV-2 (SARS2) and, as a consequence, does not respond to the infection like it can with typical pathogens that have co-evolved during pre-human and human evolution. Further, we discussed that this allows autoimmune antibodies to develop to the target ACE2 cells to bind and enter into cells. We also alluded to the role of the anti-ACE2 antibodies causing some of the dysfunction and non-well-being in patients with COVID-19, as well as with post-COVID-19. Here, we will expand the discussion of autoimmunity caused by COVID-19 infection.

> *The overall message is that COVID-19 infection adversely affects immune system function and results in autoimmunity.*

One of the first studies that discussed a broad autoimmune response due to COVID-19 was conducted by Aaron Ring, MD, PhD, and colleagues at Yale University.[1] These researchers investigated 194 individuals who previously had mild to severe COVID-19 infection, and found the severity of disease did not greatly influence the number of developing autoantibodies. Specifically, they found persons with mild symptoms could develop as many autoantibodies as those with severe symptoms. A testing panel that consisted of 2,770 human extracellular proteins that evaluated the development of autoantibodies by these subjects found that these individuals may have more than 1,000 autoantibodies after COVID-19, and any tissue in the body could have autoantibody formation. For example, 29 different proteins associated with the central nervous system could have autoantibodies directed toward them, and there was clinical correlation with a measure of brain dysfunction. They also found that a significant number of the autoantibodies have direct adverse effects on immune system function. Further, they investigated for these in mice, and demonstrated their immune system malfunctions were due to these autoantibodies. Subsequently, there have been many similar articles published. The overall message is that COVID-19 infection adversely affects immune system function and results in autoimmunity.

A more recent study[2] explored and provided evidence for continued T lymphocyte dysfunction, as well as dysfunction in the so-called adaptive immune responses. Once again, the findings showed T lymphocytes and B lymphocytes (considered the adaptive immune system components) were not functioning as intended for a normal immune response and, indeed, were in a disarray regarding how they should be interacting, resulting in autoimmunity.

A very recent study[3] indicates how the microbiome further influences the abnormal immune response to COVID-19, including aspects of the so-called innate immune system. Innate immunity has a role in the initiation of an immune response, which then influences the adaptive immune response of T and B lymphocytes. The authors, citing my and colleagues' studies on this subject, stress the importance of anti-ACE2 antibodies in post-COVID-19 infection autoimmunity issues.

All of this means the human immune system, innate and adaptive, did not evolve in a manner to deal with SARS2 infection and COVID-19 due to the lack of co-evolution. As a consequence, during the acute infection and post-infection states, immune system dysfunction creates problems and results in autoimmunity. While this appears to be affecting everyone to some extent, some individuals have a greater adverse impact than others.

In the next column, I will discuss more about SARS2 and COVID-19. IG

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Understanding Conventional vs. Functional Medicine

By Michelle Greer, RN, IgCN

NAVIGATING the healthcare system can be daunting, from knowing who to see for a new complaint and understanding your diagnosis and treatment options, to getting a handle on how reimbursement works for care and services. With choices galore and information only a click away, it can be overwhelming to know what direction to take.

The first step is to choose a healthcare provider, and part of that decision is to ensure his or her treatment philosophies align with yours: Do you prefer a mainstream, conventional approach or an alternative, holistic approach to healthcare? Your answer will determine whether to choose to utilize conventional medicine, functional medicine or a combination of the two. Let's look at these modalities in more depth.

> *Requirements for practicing functional medicine are not standardized, and the training, while extensive, varies from program to program.*

Conventional Medicine

Conventional medicine comprises the mainstream healthcare system in which medical doctors (MDs) and other healthcare professionals such as nurses, physician associates (PAs), pharmacists and therapists address symptoms and treat diseases using pharmaceutical drugs, radiation or surgery. Conventional medicine is also known as Western medicine, mainstream medicine, orthodox medicine, allopathic medicine and biomedicine.[1] MDs are physicians who have earned advanced doctorate degrees in medicine and are licensed to practice it. Treatment strategies are based on scientific research backed by clinical trials that prove efficacy. Conventional medicine relies on methods proved to be safe and effective with carefully designed trials and research.[2]

During a first encounter in conventional medicine, physicians collect and review a complete health history of their patients by asking about each system of the patients' bodies and also collecting information about the health history of patients' families. They then do an examination and explore the areas of patients' concerns in more detail. Tests such as blood work or imaging may then be ordered, after which physicians will then determine a diagnosis and prescribe medication and/or other treatments that have been proven to alleviate the symptoms or cure or remit the condition in other patients.

There are numerous ways to find a conventional medicine physician. Conducting an Internet search and exploring practitioners that are part of your health insurance network is a good place to start, but you may want to browse the many physician review networks that provide a background and reviews from other patients. If you already have a diagnosis, patient advocacy groups that specialize in your condition are a good resource to find a specialist and access patient recommendations.

Functional Medicine

Functional medicine is an alternative to the mainstream healthcare system in which medical practitioners employ a different approach to find and address the root cause of patients' symptoms. Functional medicine zooms out and considers the full picture of patients' physical, mental, emotional and sometimes even spiritual health and how they work together, then drills down to find the root of the problem. Care is "patient-centered," which means providers spend time learning about patients' lifestyles, medical histories, family histories and individual needs to find a personalized solution to their unique health problems.[3] They use specialized training, techniques and treatments to address concerns.

Considered to be more natural and holistic than conventional medicine, functional medicine emphasizes nutrition, stress reduction and movement, and treatment plans may involve implementing lifestyle changes, using herbs and supplements and alternative treatments such as acupuncture, light therapy and even saunas. However, not all the treatments have scientific evidence to support their use in the conditions treated.

Doctors of osteopathic medicine (DOs) often practice functional medicine. Like MDs, they have earned advanced degrees in medicine and are licensed to practice it; however, DOs focus on holistic health. It's important to know that not all functional medicine practitioners are MDs or DOs. PAs and chiropractors often practice functional medicine, too. Some practitioners may have additional certifications in functional medicine and other holistic approaches, but requirements for practicing functional medicine are not standardized, and the training, while extensive, varies from program to program. The expertise of functional medical providers can vary.[4]

Sometimes, treatment modalities used in functional medicine have not been studied, trialed or approved by a governing body. However, the National Center for Complementary and Integrative Health (NCCIH), part of the National Institutes of Health (NIH), is working to change this. It uses rigorous scientific investigation to determine the fundamental science, usefulness and safety of the complementary and integrative health approaches used in the practice of functional medicine and their role(s) in improving health and healthcare. NCCIH's vision is for scientific evidence to inform decision-making by the public, healthcare professionals and health policymakers regarding the integrated use of complementary health approaches in a whole person health framework.[5]

Functional medicine is gaining popularity, so finding a credentialed functional doctor in your geographic area may be easy. An Internet search for "functional medicine doctors near me" can be a good starting point. However, it's important to note that not all functional medical services will be covered by health insurance.

Integrative Medicine

Integrative medicine is a combination of conventional and functional medicine. This modality recognizes the benefit of combining standard therapies (such as prescription drugs and surgical procedures) with alternative therapies (such as nutritional changes, supplements, yoga or Tai Chi, meditation and massage). For example, a cancer patient's treatment plan may include both drugs to fight cancer and acupuncture to help ease pain, nausea and vomiting. Like functional medicine, integrative medicine also considers the physical, emotional, social, spiritual and environmental factors that contribute to patients' overall well-being.[6]

Many of the leading healthcare systems in the United States currently have departments dedicated to integrative medicine, including:

- Cleveland Clinic's Center for Functional Medicine
- Johns Hopkins Integrative Medicine and Digestive Center
- Mayo Clinic Integrative Medicine and Health
- MD Anderson Integrative Medicine Center

Local and regional health systems near you may have similar departments that combine standard and alternative treatment modalities.

Which Is Best for You?

No matter which approach you take, the goal remains the same: high-quality care that prioritizes patient needs and optimizes patient outcomes. Some patients prefer proven methods of conventional medicine, while others want to consider their health from an alternative angle. Whether you see an MD or a DO, rely on a daily medication or implement a myriad of lifestyle changes — or some combination of all these options — make sure you are comfortable with your doctor's treatment philosophy, ask lots of questions so you understand your diagnosis and treatment plan, and speak up if you have a concern. Your doctor is an integral part of your healthcare team, but you are too. IG

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RESEARCH

Study Finds New Cause of SCID and Omenn Syndrome

A study conducted by a team of researchers at Newcastle University has identified a novel genetic reason for immunological illnesses — severe combined immunodeficiency (SCID) and Omenn syndrome (OS) — that are uncommon in children, which could lead to early detection and treatment.

The study involved specialists from Newcastle University, the Great North Children's Hospital in Newcastle, the Wellcome Sanger Institute and its partners in the Netherlands, Norway and the United Kingdom. Eleven children, two of whom had SCID and the other nine who had OS, from four distinct families were evaluated by the team. The 11 children were all discovered to have hereditary mutations that interfered with the NUDCD3 protein's ability to function. The T and B cells required to fight various infections were unable to mature normally as a result of these abnormalities.

The researchers found through in-depth analyses of patient-derived cells and mice models that NUDCD3 mutations impede a crucial gene-rearranging mechanism known as V(D)J recombination. The production of the many T cell receptors and antibodies required to identify and combat various infections depends on this mechanism. They discovered that, in contrast to mice created with the same NUDCD3 mutations, who had less severe immunological issues, human patients faced serious, perhaps fatal repercussions.

The discovery of this novel illness gene will enable medical professionals to diagnose afflicted people with a new disease more rapidly and provide them with lifesaving therapies. The results of this study pave the way for early SCID and OS diagnosis, intervention and genetic counseling for impacted families. While T cell deficiency can be identified by newborn screening techniques, understanding the precise genetic etiology of SCID boosts diagnostic confidence and influences the selection of a curative treatment.

According to Sophie Hambleton, MD, from Newcastle University, who is also employed as a pediatric immunologist at the Great North Children's Hospital, "We can better care for impacted babies if we have a deeper understanding of its underlying causes. While we continue to learn more about how the immune system functions in both health and disease, our research aims to fill in the gaps so that families can obtain a molecular diagnosis."

Researchers Identify New Cause of Severe Combined Immunodeficiency and Omenn Syndrome. Financial Express, Sept. 23, 2024. Accessed at www.financialexpress.com/life/science-researchers-identify-new-cause-of-severe-combined-immunodeficiency-and-omen-syndrome-3618924.

MEDICINES

Xembify Receives Expanded Label for PI Patients

The U.S. Food and Drug Administration (FDA) has approved an expanded label for Grifols' XEMBIFY (20% subcutaneous immune globulin [SCIG]) to include treatment-naïve patients with primary humoral immunodeficiencies (PI). Approval makes XEMBIFY the first 20% SCIG with this extended label, allowing patients to begin SCIG therapy without first having intravenous administration. Approval of the supplemental biologics application also includes biweekly dosing.

Approval is based on data from a Phase IV multicenter, single-sequence, open-label clinical trial that included 27 subjects across 18 U.S. sites, which met its primary endpoint, demonstrating that patients with PI treated with XEMBIFY every two weeks achieved non-inferiority in total IG levels compared with those who received the medication every seven days. There were no unique safety issues identified in the trial, and the tolerability profiles were consistent between biweekly and weekly administration.

"The XEMBIFY label expansion eliminates the need for patients to have initial intravenous treatment, which differentiates XEMBIFY from other SCIG therapies, plus offers patients greater convenience and flexibility with biweekly dosing," said Joerg Schuettrumpf, chief scientific innovation officer at Grifols. "Grifols plans to launch the new label in the U.S. in the third quarter of 2024 as part of the company's commitment to increasing options for patients and adapting to their needs and lifestyles."

Grifols Receives Expanded XEMBIFY® (Immune Globulin Subcutaneous Human-klhw) Label in U.S., Strengthening Its IG Portfolio for Patients. Grifols press release, July 29, 2024. Accessed at www.biospace.com/grifols-receives-expanded-xembify-immune-globulin-subcutaneous-human-klhw-label-in-u-s-strengthening-its-ig-portfolio-for-patients.

RESEARCH

Study Shows Stem Cell Editing Repairs Severe Immunodeficiency

In a study published in *Science Translational Medicine*, researchers developed an efficient method to repair recombination activating gene 1 (RAG1) genes in immune cell progenitors called hematopoietic stem cells (HSC) taken from severe combined immunodeficiency (SCID) patients, and revealed that they could restore immune function in mice.

RAG1 is central to this shapeshifting behavior of using B-cell and T-cell receptors, which take on various shapes to bind to different antigens on foreign invaders. It shuffles the order of DNA sequences in the genes for these receptors, producing multiple versions of the immune receptors that can bind staggering combinations of antigens. However, some people carry mutations in RAG1 that prevent the enzyme from recombining the DNA sequences that code for these receptors. Without properly functioning receptors, B and T cells fail to develop, leading to SCID, a condition in which even the mildest of infections can prove lethal.

In their study, the researchers set out to overcome some of the challenges with editing the RAG1 gene that researchers previously faced. In the past, scientists have taken healthy, functional HSC and inserted them into SCID-model mice, but they often get destroyed by other types of immune cells that recognize the transplants as foreign. Normally, doctors use immunosuppressants like chemotherapy before transplantation to deplete immune cells, but this isn't an option for SCID patients.

So, they modified a SCID patient's own stem cells to express a functional RAG1 gene. While other research groups had successfully added RAG1 to patient HSC, they were unable to properly regulate expression of the gene, and therefore couldn't ensure that the stem cells were safe or would effectively replenish B and T cells. Introducing the gene into the wrong site in the genome may have partly caused this shortcoming.

Rather than adding a functional copy of RAG1, the researchers decided to modify the existing copy, ensuring that the regulatory networks remained intact. Before they could fix the gene, however, they had to choose their editing strategy. They used the clustered regularly interspaced short palindromic repeats (CRISPR-Cas9) system to cut out a large section of the mutant gene, and then provided cells with the correct DNA sequence using a lentiviral delivery system. Since the correct sequence was nearly identical to the original gene, the cell could swap the sequences unassisted using homology-directed repair (HDR), a built-in DNA repair pathway that fixes double-strand DNA breaks using complementary DNA as a template.

Once they swapped the HSC's old, mutated coding sequence for a fresh one, they had to test whether the gene produced a functional RAG1 protein. They inserted a backwards green fluorescent protein (gfp) gene flanked by sequences that RAG1 recognizes. Promisingly, they found that the edited RAG1 inverted gfp comparably to RAG1 in HSC from healthy donors, thereby switching it to an "on" state, resulting in a functional gfp gene.

Next, they checked that these edited cells could restore immune function in the body. They transplanted these edited human cells into SCID-model mice and found that B and T cells spiked to levels similar to those seen in mice that received HSC from healthy donors. "What's intriguing from the study is that we don't need to correct all the stem cells. If we manage to correct at least 10 percent of the stem cells, this is going to give us a therapeutic benefit," said Saravanabhavan Thangavel, MD, a geneticist at the Institute of Stem Cell Research and Regenerative Medicine who was not involved with the work. However, he also mentioned, "We need to track the HDR-edited cells long term." The researchers need to ensure that the modified cells persist in the bodies of people with SCID so that their newly gained immunity doesn't wane over time. "If, by chance, the HDR-edited cells faded away, they may not have a therapeutic benefit," Dr. Thangavel added.

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RESEARCH

Neoself-Antigens Found to Induce Autoimmune Response in Lupus

Researchers from Osaka University in Japan have revealed that human proteins with an unusual structure trigger an inflammatory response by immune cells, which leads to autoimmunity. Autoimmune diseases develop when the body's immune system mistakenly attacks its own tissues instead of fighting off foreign invaders. Researchers are still trying to understand why this happens.

"T cells have been thought to discriminate between small fragments of protein derived from self and non-self proteins presented on the major histocompatibility complex II (MHC-II), and 'trained' not to respond to self-antigens," explained senior author of the study Hisashi Arase. "However, when the MHC-II is missing a crucial piece called the invariant chain (Ii), it can present larger, misfolded self-antigens, called neoself-antigens, to T cells."

Autoantibodies to neoself-antigens are often found in patients with autoimmune diseases, so the researchers explored T cell reactivity in patients with lupus and in mice, in which Ii was depleted in adults. They also examined the effect of Epstein–Barr virus (EBV) infection, a risk factor for lupus, on T cell reactivity to neoself-antigens.

"We found that approximately 10 percent of clonally expanded T cell repertoire in lupus patients recognized neoself-antigens. Furthermore, induction of neoself-antigens induced lupus-like disease in mice, meaning that they mounted an immune response to the body's own tissues, thereby causing autoimmune disease," said lead author Shunsuke Mori.

The researchers also found that reactivation of EBV increases the presentation of neoself-antigens on MHC-II through downregulating the expression of Ii, triggering the activation of T cells directed against the body. This could explain why EBV reactivation is linked to the onset or exacerbation of lupus.

"Our findings demonstrate that T cells discriminate self- and neoself-antigens and do not recognize neoself-antigens as self antigens, thus leading to the development of autoimmunity when neoself-antigens are presented on MHC-II," says Arase.

This study substantially increases our understanding of self-tolerance of T cells, as well as the causes of autoimmune disease, by identifying neoself-antigens as a distinct class of antigens that trigger an inappropriate immune response. IG

Osaka University. Neoself-Antigens Found to Induce Autoimmune Response in Lupus. Medical Xpress, Sept. 13, 2024. Accessed at medicalxpress.com/news/2024-09-neoself-antigens-autoimmune-response-lupus.html.

MEDICINES

FDA Gives Fast Track Designation to Abata Therapeutics' ABA-101 for the Treatment of MS

The U.S. Food and Drug Administration (FDA) has granted fast track designation for Abata Therapeutics' ABA-101 for the treatment of multiple sclerosis (MS). "We are very pleased that the FDA granted us fast track designation, as it will enable us to expedite our efforts to bring ABA-101 to patients," said Samantha Singer, MS, MBA, president and chief executive officer of Abata. "We are focused on initiating our Phase I study this year in patients and evaluating the potential impact of this important new therapy."

Abata is developing ABA-101 as an autologous Treg therapy to treat patients with progressive disease who have imaging evidence of ongoing inflammatory tissue injury and are HLA-DRB1*15:01 positive, an estimated patient group of about 45,000 in the United States today. ABA-101 is created by engineering a patient's own Tregs to express a T cell receptor that specifically recognizes immunogenic myelin fragments in the central nervous system. This approach was designed to offer a strong safety profile and a highly localized anti-inflammatory effect at the site of disease. In vivo preclinical studies showed that ABA-101 was well-tolerated and demonstrated antigen-dependent Treg functionality, anti-inflammatory cytokine production, suppression of the production of inflammatory cytokines and therapeutic effect. IG

Abata Therapeutics Receives FDA Fast Track Designation for ABA-101 for the Treatment of Progressive Multiple Sclerosis. FirstWord Pharma press release, Aug. 22, 2024. Accessed at firstwordpharma.com/story/5888305.

RESEARCH

Combination Vyvgart and Steroid Therapy Resolves Myasthenic Crisis

A case study of a 70-year-old Japanese woman with generalized myasthenia gravis (gMG) showed that combining Vyvgart (efgartigimod) with steroid therapy resolved a myasthenic crisis, a potentially life-threatening complication of myasthenia gravis (MG) that involves severe breathing problems. "To the best of our knowledge, this is the first case of gMG to show the efficacy of [Vyvgart] during the acute phase of a myasthenic crisis without using IVIG [intravenous immune globulin] or [plasmapheresis]," the researchers wrote.

MG is an autoimmune disease in which the immune system targets and attacks proteins required for nerve-muscle communication, causing muscle weakness and fatigue. MG is usually caused by self-reactive antibodies that target acetylcholine receptors (AChRs) on muscle cells, interfering with normal muscle contraction. Patients are at risk for a myasthenic crisis that requires hospitalization when muscle weakness affects muscles involved in breathing. Breathing support and plasmapheresis or IVIG are often used to quickly ease symptoms during an emergency.

Vyvgart eases MG symptoms by lowering the levels of disease-causing autoantibodies in the bloodstream. In the U.S., it's approved to treat adults with gMG who are positive for anti-AchR antibodies, while in Japan it is approved for adults with gMG who do not sufficiently respond to steroids or non-steroidal immunosuppressive therapies regardless of their antibody status.

Phase III trials that established Vyvgart's efficacy at easing gMG symptoms excluded patients who'd had a myasthenic crisis, making it unclear if Vyvgart might be effective for the complication. "Our case suggests that [Vyvgart] can be an alternative drug for achieving minimal manifestation status in patients with myasthenic crisis," the researchers wrote. "Considering its strong efficacy and safety, [Vyvgart] could be expanded to use as bridging therapy in the acute and chronic phases of gMG."

Poinsatte, K. Vyvgart, Steroid Therapy Used as Treatment for Myasthenic Crisis. Myasthenia Gravis News, Sept. 4, 2024. Accessed at myastheniagravisnews.com/news/vyvgart-steroid-therapy-treatment-womans-myasthenic-crisis.

MEDICINES

Tremfya Receives FDA Approval for Adults with Moderate to Severe Ulcerative Colitis

The U.S. Food and Drug Administration (FDA) has approved Johnson & Johnson's Tremfya (guselkumab) for the treatment of moderately to severely active ulcerative colitis (UC) in adults who experienced an inadequate response or who demonstrate intolerance to conventional therapy, other biologics and/or JAK inhibitors. UC is a chronic disease of the large intestine in which the lining of the colon becomes inflamed.

Tremfya is the first and only FDA-approved fully-human, dual-acting monoclonal antibody that blocks IL-23 while also binding to CD64, a receptor on cells that produce IL-23. IL-23 is a cytokine secreted by activated monocyte/macrophages and dendritic cells that is known to be a driver of immune-mediated diseases, including UC.

"Treatment with Tremfya resulted in significant improvement in the chronic symptoms of ulcerative colitis and, importantly, normalization in the endoscopic appearance of the intestinal lining," said David T. Rubin, MD, director of the Inflammatory Bowel Disease Center at the University of Chicago Medicine, and lead investigator of QUASAR, the clinical program investigating Tremfya. "Today's approval of Tremfya builds on the clinical and well-established safety profile of this IL-23 inhibitor and marks a significant step forward in the treatment of this chronic inflammatory disease."

"In the QUASAR clinical program, Tremfya demonstrated high reported rates of endoscopic remission at one year of treatment, continuing to raise the bar for efficacy in the treatment of this inflammatory bowel disease," said Christopher Gasink, MD, vice president of medical affairs in the gastroenterology and autoantibody division of Johnson & Johnson Innovative Medicine.

Tremfya (guselkumab) Receives U.S. FDA Approval for Adults with Moderately to Severely Active Ulcerative Colitis, Strengthening Johnson & Johnson's Leadership in Inflammatory Bowel Disease. Prnewswire, Sept. 11, 2024. Accessed at www.prnewswire.com/news-releases/tremfya-guselkumab-receives-us-fda-approval-for-adults-with-moderately-to-severely-active-ulcerative-colitis-strengthening-johnson--johnsons-leadership-in-inflammatory-bowel-disease-302245763.html.

INDICATIONS AND USAGE

PANZYGA (Immune Globulin Intravenous [Human] – ifas) is indicated for the treatment of primary humoral immunodeficiency (PI) in patients 2 years of age and older, chronic immune thrombocytopenia (cITP) in adults and chronic inflammatory demyelinating polyneuropathy (CIDP) in adults.

PANZYGA 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. For patients with PI, PANZYGA helps replace the missing antibodies in the body. For patients with cITP, PANZYGA helps the body produce more platelets (the blood cells that help blood clot) to control or prevent bleeding. For patients with CIDP, PANZYGA may help improve mobility and hand strength.

PANZYGA is given into a vein (intravenously) in a hospital, infusion center, doctor’s office, or at home by a trained healthcare provider (HCP).

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS, RENAL DYSFUNCTION, and ACUTE RENAL FAILURE

See full prescribing information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin intravenous (IGIV) products, including PANZYGA. 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.**
- **Renal dysfunction, acute renal failure, osmotic nephropathy, and death may occur with the administration of IGIV products in predisposed patients. Renal dysfunction and acute renal failure occur more commonly in patients receiving IGIV products containing sucrose. PANZYGA does not contain sucrose.**
- **For patients at risk of thrombosis, renal dysfunction, or acute renal failure, administer PANZYGA at the minimum 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.**

Do not use PANZYGA if you:

- Have had a severe allergic reaction to immune globulin or other blood products
- Have a condition called selective (or severe) immunoglobulin A (IgA) deficiency, with antibodies against IgA and a history of hypersensitivity

What should I know before taking PANZYGA?

- PANZYGA can make vaccines (like measles/mumps/rubella or chickenpox vaccines) work less effectively for you. Before you get any vaccines, tell your healthcare provider that you take PANZYGA
- Decreased kidney function and kidney function failure can occur
- Severe headache, drowsiness, fever, painful eye movements, or nausea and vomiting can occur
- Elevated blood pressure can occur particularly in patients who have a history of hypertension (high blood pressure)
- If you are elderly, with heart or kidney problems, discuss with your healthcare provider prior to initiating treatment with PANZYGA
- PANZYGA is made from human blood and therefore may have a risk of transmitting infectious agents, including viruses and, theoretically, the variant Creutzfeldt-Jakob disease (CJD) and CJD agent. The production and manufacturing process reduces this risk, but the risk cannot be eliminated

PANZYGA can cause serious side effects. If any of the following problems occur after starting PANZYGA, 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, drowsiness, painful eye movements, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain

Please see Important Safety Information on this and adjacent page of this advertisement and Brief Summary of Prescribing Information.

FDA approved for chronic inflammatory demyelinating polyneuropathy (CIDP) in adults to improve neuromuscular disability and impairment

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Immune Globulin
Intravenous (Human) - ifas
10% Liquid Preparation

- **80% treated with 1g/kg and 92% treated with 2g/kg of PANZYGA saw improvement in arm and/or leg impairment***
- **With the PANZYGA Co-Pay Program, eligible patients may pay as little as $0 for PANZYGA†**
  - Patients must have commercial insurance to be eligible
  - Patients are not eligible if they are enrolled in a state or federally funded insurance program

Talk to your doctor about PANZYGA and learn more at PanzygaInfo.com

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*Depending on the ongoing therapy dose.

†Eligible, commercially insured patients may pay as little as $0 for PANZYGA and may receive a maximum benefit of $12,500 per year or the cost of patient's co-pay in a 12-month period (whichever is less) for claims received by the program. Terms and conditions/eligibility requirements apply. See full Terms and Conditions at PanzygaCoPay.com.

IMPORTANT SAFETY INFORMATION (continued)

- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem (decreased kidney function or kidney failure)
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot, which could happen in the heart, brain, lungs, or elsewhere in the body
- Brown or red urine, swelling, fatigue, fast heart rate, difficulty breathing, or 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
- Headache, fatigue or confusion, vision problem, chest pain, difficulty breathing, irregular heartbeat, or pounding in your chest, neck, or ears. These could be signs of high blood pressure

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

What are the possible or reasonably likely side effects for PANZYGA?

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

- Headache
- Nausea
- Fever
- Increased blood pressure
- Dermatitis
- Fatigue
- Abdominal pain
- Dizziness
- Anemia

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.

Tell your HCP if you are pregnant, or plan to become pregnant, or if you are nursing.

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 & 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.

PANZYGA® is a registered trademark of Octapharma AG.

PANZYGA is FDA approved for 3 indications:

CIDP in adults
PI in patients 2 years of age or older
cITP in adults

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Manufactured by Octapharma Pharmazeutika Produktionsges m.b.H. Distributed by Pfizer Labs, Division of Pfizer inc.

April 2024

panzyga®
Immune Globulin
Intravenous (Human) - ifas
10% Liquid Preparation

CONSUMER BRIEF SUMMARY

(PANZYGA: *pan-zee-guh*)

This brief summary highlights the most important information about PANZYGA. Please read it carefully before using PANZYGA 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 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.PanzygaInfo.com.

What is PANZYGA?

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

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This brief summary is based on the PANZYGA Prescribing Information (February 2021).

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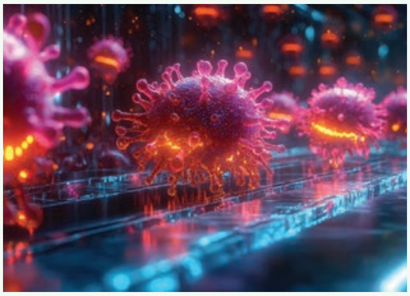
RESEARCH

FDA Approves Iaso Bio IND to Test CAR T-Cell Therapy in New Autoimmune Indications



The U.S. Food and Drug Administration (FDA) has granted China-based Iaso Biotherapeutics (Iaso Bio) permission to begin clinical trials of its autologous BCMA-targeted CAR T-cell therapy equecabtagene autoleucel (eque-cel) in two new autoimmune diseases in the United States. In China, eque-cel is branded as Fucaso and received marketing approval from China's National Medical Products Administration last year as a treatment for certain patients with relapsed and/or refractory multiple myeloma. It also received permission to test eque-cel in neuromyelitis optica spectrum disorder and myasthenia gravis.

In the United States, FDA has approved investigational new drug applications allowing the company to test the cell therapy in myasthenia gravis and multiple sclerosis.

"Clinical trial data from China have demonstrated eque-cel's significant efficacy and safety in treating relapsed/refractory autoantibody-mediated neurological diseases," said Yongke Zhang, chief strategy officer of Iaso Bio. "We believe it holds similar promise for other autoimmune diseases, such as [non-renal systemic lupus erythematosus] and [lupus nephritis], where autoantibodies play key pathogenic roles."

FDA Approves Iaso Bio IND to Test CAR T-Cell Therapy in New Autoimmune Indications. Precision Medicine Online, Aug. 14, 2024. Accessed at www.precisionmedicineonline.com/regulatory-news-fda-approvals/fda-approves-iaso-bio-ind-test-car-t-cell-therapy-new-autoimmune.

Medical Gaslighting

A Growing Concern in Modern Healthcare

Dismissive attitudes by healthcare providers compromise the doctor/patient relationship and lead to misdiagnosis, delayed treatment and a breakdown of trust.

By Trudie Mitschang

MEDICAL GASLIGHTING is a term that has gained traction in recent years, describing a phenomenon in which a healthcare provider dismisses or downplays a patient's symptoms, often leading to misdiagnosis or delayed treatment. This practice can have severe implications for patients, particularly those who already face barriers in accessing healthcare such as women, minorities and people with chronic illnesses.

The American Psychological Association defines gaslighting as manipulating another person into doubting his or her perceptions, experiences or understanding of events. The term itself derives from a 1944 classic movie by the same name, in which a woman is slowly driven insane by her manipulative husband who causes her to question her perception of reality when he secretly hides her belongings and gradually dims their home's gas-fueled lights.

In the medical context, this behavior often manifests when a healthcare professional minimizes or disregards a patient's symptoms or concerns and instead attributes them to anxiety, stress or an overactive imagination rather than investigating them further. As a result, patients may begin to question their judgment, feel invalidated and delay seeking further medical care, all of which can potentially exacerbate their conditions.

"Gaslighting can be differentiated from other forms of bullying in medicine because it does not involve public humiliation, specific threats or blatant insults," says Sarah Fraser, MSc, MD, CCFP, a general practitioner and the Editorial Fellow for *Canadian Family Physician*. "Gaslighting is more subtle than that. More private. This makes it all the more dangerous because it can remain invisible. While it might not result in full-blown delusions or distortions of memory, this abuse can have lasting effects on self-esteem and mental health."[1]

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Understanding the Role of Bias

Historically, women in particular have been the victims of medical gaslighting. Conditions like hysteria, a diagnosis that was common during the 19th century, were used to pathologize a wide range of symptoms in women, from anxiety to chronic pain, without addressing the underlying causes. Today, whether it is heart disease mislabeled as anxiety, an autoimmune disorder attributed to depression or ovarian cysts chalked up to "normal period pain," many women's health issues are statistically more likely to be misdiagnosed or dismissed by doctors as something less critical. One study published in *Academic Emergency Medicine* found that women who went to the emergency room with severe stomach pain had to wait for almost 33 percent longer than men with the same symptoms.[2]

"It's a true phenomenon," says G. Thomas Ruiz, MD, lead OB/GYN at MemorialCare Orange Coast Medical Center in Fountain Valley, Calif. "Gender bias is a harsh opinion as to why [it happens], but there's some pretty good research to support that."[3]

"It's no accident that the word 'hysteria' originates from the Greek word for 'uterus,'" notes OB/GYN Stephanie Trentacoste McNally, MD. "There's still this pervasive belief in the medical community that anytime a woman complains about her health, it's either related to her hormones or all in her head. Female hysteria was once a common medical diagnosis for women, applied whenever women displayed 'inappropriate' emotions such as anxiety, anger and even sexual desire. For centuries, it was believed that the uterus itself was the cause of a woman's 'hysterical' symptoms."[4]

Of course, when we discuss bias in the medical community, it's not just women who are negatively impacted. A report from the Institute of Medicine highlights that racial and ethnic minorities receive lower-quality healthcare than white patients, even when controlling for factors such as insurance status and income.[5] This can amplify instances of medical gaslighting, since providers may unconsciously or consciously downplay the concerns of these patients.

David Williams, MPh, PhD, a Harvard University professor and health disparity researcher, explains, "Medical gaslighting is a symptom of a larger problem in healthcare — the systemic biases that lead to unequal treatment. Addressing this issue requires not only awareness but also concrete actions to train healthcare providers to recognize and counteract their biases."[6]

Gaslighting and Chronic Illness

Medical gaslighting is sadly too common when it comes to the diagnosis and treatment of patients with chronic illnesses such as fibromyalgia, chronic fatigue syndrome and autoimmune diseases, which tend to be poorly understood and frequently dismissed by medical professionals. Ilana Jacqueline, a primary immune deficiency patient and patient advocate, recently authored the book *Medical Gaslighting: How to Get the Care You Deserve in a System that*

Makes You Fight for Your Life. According to Jacqueline, the intersectionality of gender and chronic illness is especially fraught with the risk of gaslighting.

“When you encounter bias as a woman in the exam room, it’s going to look like tracing symptoms back to anxiety or depression, eating disorders and other mental illnesses with no actual testing taking place before coming to that conclusion,” explains Jacqueline. “I think just being aware of this bias can help so many patients to not accept that as an adequate answer from a doctor, especially one that isn’t a licensed psychologist or psychiatrist but say, a gynecologist, an emergency room doctor or another specialist.”[7]

Jacqueline describes a personal encounter when a male doctor dismissed her chronic pain symptoms and refused to run adequate tests: “He sneered at my explanations of pain, shamed me for not managing my condition how he thought it should be managed. Even though I was compliant with his treatment plan and polite back to him, he continued to talk down to me.”

She says this dynamic continued until she made the life-changing decision to bring her husband with her into the exam room. “My symptoms were so bad that I couldn’t drive myself and had my husband tag along,” says Jacqueline. “With a man in the room, the doctor’s demeanor instantly changed. He was no longer rude or condescending, he had concern instead of blame when I discussed the treatments not working, and he gave me options for other treatments he’d never brought up before. He also spent most of the session directing his advice for me to my husband.”[7]

> **When a physician refuses to take a patient’s symptoms seriously, he or she is actually keeping that patient from the treatment plan needed to feel better.**

Patients who live with a chronic illness, especially an invisible one, can feel like others don’t understand what they are going through. Because of that, people around them may be reluctant to believe they are truly ill or tell them: “You don’t look sick.” While these experiences cause their own emotional distress, there is a distinction between someone not understanding what someone is going through and someone in a position of power, such as a physician or other medical professional, actively gaslighting that person. When a physician refuses to take a patient’s symptoms seriously, he or she is actually keeping the patient from the treatment plan needed to feel better.

Assessing the Psychological and Physical Toll

The psychological effects of medical gaslighting can be profound. Patients who experience this form of dismissal may develop anxiety, depression and a deep mistrust of the medical system. This mistrust can prevent them from seeking care in the future, leading to worsened health outcomes. For some patients, the experience of medical gaslighting can be retraumatizing, particularly for those with a history of trauma. Being dismissed or not believed by a trusted authority figure, such as a doctor, can trigger past trauma and exacerbate symptoms of post-traumatic stress disorder.

“Before a medical appointment, [someone who has been gaslit] may mentally go through all of the worst things the doctor, nurse or staff may say or do, and think a lot about how to respond,” explains Melissa Geraghty, PsyD, a licensed clinical health psychologist who has experienced medical gaslighting herself as she navigated disabilities and pain. “Gaslighting can make you question yourself and the validity of your pain. You wonder if your symptoms are really ‘bad enough’ to get treatment.”[8]

Even if individual doctors are not intending to cause harm, medical gaslighting can have severe consequences for patients who are already dealing with the burden of chronic illness, including:

- *Delayed diagnosis*. When doctors dismiss or downplay symptoms, it can lead to a delayed diagnosis, which is particularly damaging for conditions that require early intervention for better outcomes.
- *Inadequate treatment*. Medical gaslighting often results in unsuccessful treatment plans or a lack of appropriate referrals to specialists. Patients are left without the care they need to manage their symptoms effectively.
- *Self-doubt*. Over time, patients who experience gaslighting may start to doubt their own experiences, which can lead to a loss of self-trust and loss of trust in the medical profession.

- *Worsening symptoms*. The stress and anxiety caused by medical gaslighting can actually make symptoms worse.

An Empowered Path Forward

Addressing medical gaslighting requires a multifaceted approach, involving both systemic changes in healthcare and empowering patients to advocate for themselves. Here are some expert-recommended solutions:

- *Education and training for healthcare providers*. One of the primary ways to combat medical gaslighting is through better education and training for healthcare providers. This includes training on implicit bias, communication skills and the importance of listening to and validating patient concerns.
- *Patient advocacy and empowerment*. Patients need to be empowered to advocate for themselves in medical settings. This can involve educating patients on their rights, encouraging them to seek second opinions and providing resources to help them navigate the healthcare system.
- *Policy changes and accountability*. There is also a need for policy changes that hold healthcare providers accountable for medical gaslighting. This could include stricter regulations on patient complaints, more robust systems for reporting and addressing bias in healthcare, and greater transparency in medical decision-making processes.
- *Increased research and awareness*. Continued research into the prevalence and impact of medical gaslighting is essential. Studies that document patient experiences can help raise awareness about the issue and drive changes in both policy and practice. In addition, awareness campaigns aimed at both healthcare professionals and the general public can help destigmatize the reporting of medical gaslighting and encourage more open dialogue about the issue.

A Complex Issue

Medical gaslighting is a complex issue requiring engagement from both practitioners and patient communities. By educating healthcare providers, empowering patients, implementing policy changes and continuing research, the healthcare system can begin to dismantle the structures that allow medical gaslighting to persist, especially for women and marginalized communities.

"Medicine is a profession that patients' approach from a place of vulnerability and that requires trust," says medical psychologist Ingela Thuné-Boyle, PhD. "Indeed, the core of medicine should be humility; healing happens when the physician is present with the patient, not because they know everything."[9]

Tips for Coping with Medical Gaslighting

If you have suffered from medical gaslighting or invalidation within the healthcare system, here are some tips to help you move forward with more self-assurance and confidence:

Trust your instincts. Remember that you are the expert on your own body. If you feel that something is wrong, don't be afraid to seek a second opinion or advocate for further testing.

Be willing to "fire" your doctor. If you have a gut feeling that you were mistreated during a medical appointment, you have the right to discontinue working with that person and request a new doctor.

Have someone bear witness. Bring a trusted friend or family member with you to appointments so they can back you up if gaslighting occurs.

Learn to speak up. Ask your questions, and request further explanation, testing or referrals. It is your right as a patient.

Track symptoms. Keeping a detailed record of your symptoms, their severity and their impact can be a valuable tool when discussing your concerns with providers.

Seek support. Joining support groups or seeking guidance from others who share your diagnosis can help you feel less alone in your journey.

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

Smart Health:

How AI Is Shaping the Future of Chronic Illness Management

AI is offering tremendous advances for managing chronic conditions such as primary immunodeficiencies and autoimmune disorders, but challenges and ethical considerations need to be addressed.

By Rachel Colletta, BSN, CRNI, IgCN

AS HEALTHCARE CONTINUES to evolve, artificial intelligence (AI) is emerging as a powerful tool in disease management to enhance health outcomes for patients, including those with chronic illnesses. This technology can transform how we approach complex health issues, including primary immunodeficiencies and autoimmune disorders, by providing more personalized and efficient care.

The integration of AI in healthcare impacts various aspects of chronic disease management. Predictive analytics powered by AI help identify patients at risk of developing complications and enable early intervention. AI-enhanced monitoring systems allow for continuous patient health data tracking, assisting in timely treatment plan adjustments. Additionally, AI-driven clinical decision support systems help healthcare providers make more informed choices, which leads to improved patient outcomes. Exploring these cutting-edge technologies can provide insights into their functions and applications in modern healthcare. However, while these advancements offer significant benefits, addressing the challenges and ethical considerations associated with AI implementation in healthcare is crucial.

For those living with chronic illnesses such as a primary immunodeficiency or an autoimmune disorder, AI can help doctors understand patients' risk of complications and provide a clearer picture of what might happen next.

AI-Powered Predictive Analytics for Chronic Disease

AI-powered predictive analytics is much like having a crystal ball, especially when managing chronic diseases. This advanced technology helps doctors predict potential health issues before they become serious. Imagine if a doctor could know beforehand if a patient's condition might worsen or a new problem might arise. AI can analyze patients' health data such as lab results and medical history to spot patterns and trends that may otherwise be missed.

For those living with chronic illnesses such as a primary immunodeficiency (PI) or an autoimmune disorder, AI can help doctors understand patients' risk of complications and provide a clearer picture of what might happen next. This means doctors can act early, changing treatment plans or suggesting lifestyle adjustments before any issues become critical. By doing so, AI helps prevent emergencies and tailors the treatment to fit patients' unique needs, making it more personal and effective.

Understanding AI Algorithms for Early Detection

An AI algorithm is a set of rules and instructions a computer follows to solve problems or make data-based decisions. AI algorithms play a vital role in analyzing data from sources like wearable devices and electronic health records to detect early signs of health issues. These algorithms learn to identify patterns and trends that might indicate future health problems by looking at past patient data.

For example, in the case of heart disease, AI algorithms can process information from wearable fitness trackers and medical records to spot unusual changes in heart rate or activity levels, which could signal potential heart issues. In patients with diabetes, AI can analyze shifts in blood sugar levels and physical activity to catch warning signs early.

AI algorithms are also beneficial in detecting issues related to PI and autoimmune disorders. For PI, AI can help identify patterns in immune system markers that suggest a person's immune system is not functioning correctly, allowing for early diagnosis and treatment. In autoimmune disorders, AI can analyze changes in inflammation markers and other symptoms to detect flare-ups or changes in disease activity, helping doctors adjust treatment plans promptly.

Enhancing Patient Monitoring with AI

AI's advanced patient monitoring provides more efficient, accurate and personalized healthcare. This technology enhances the capabilities of remote monitoring tools, wearable devices and real-time data analysis, leading to improved patient outcomes and reduced healthcare costs.

Reconnect with game night

People with primary immunodeficiency (PI) who infuse CUVITRU weekly or every other week may be able to experience more of these moments.

What is CUVITRU®?

CUVITRU [Immune Globulin Subcutaneous (Human)] 20% Solution is a ready-to-use liquid medicine that is given under the skin (subcutaneously) to treat primary immunodeficiency (PI) in people 2 years and older.

IMPORTANT SAFETY INFORMATION

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

CUVITRU can cause the following serious reactions:

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

Who should not use CUVITRU?

Do not use CUVITRU if you:

- Have had a severe allergic reaction to immune globulin or other blood products.
- Have a condition called selective (or severe) immunoglobulin A (IgA) deficiency.

What should I avoid while taking CUVITRU?

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

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

CUVITRU can cause serious side effects. If any of the following problems occur after starting CUVITRU, 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.

Cuvitru
[Immune Globulin Subcutaneous (Human)] 20%

Proven protection from infection

In the North American (NA) study, there were 0.012 acute serious bacterial infections (ASBIs) per patient-year.[*,†] This exceeds the FDA standard for effectiveness, which is one serious ASBI per year.

Nearly all infusions (99.8%) were completed without reduction, interruption or discontinuation due to tolerability

No patients discontinued due to local adverse reactions (ARs) and 0 serious ARs related to CUVITRU were reported.

The most common adverse reactions observed in clinical trials in ≥5% of patients were: local adverse reactions including mild or moderate pain, erythema, and pruritus, and systemic adverse reactions including headache, nausea, fatigue, diarrhea, and vomiting.

Flexible administration that can be tailored to fit your lifestyle[‡,§]

CUVITRU can be infused at the fastest rates and highest volumes with the fewest infusion sites of any subQ IG.[§]

In the NA clinical study, CUVITRU was studied in 77 people with PI ≥2 years of age. The main goal of the study was to measure how many acute serious bacterial infections (ASBIs) were experienced over the course of 1 year. ASBIs are short-term but serious infections that require immediate medical care. ASBIs were evaluated in 74 people taking CUVITRU for an average of 380.5 days (range, 30-629 days).

[*] One ASBI that occurred during the study was a case of pneumonia in a 78-year-old person.

[†] A patient-year is a patient experience in a clinical trial over the course of 1 year. One patient-year is equal to, for example, the experience of 2 patients for 6 months, or 12 patients for 1 month each.

[‡] In the NA study, the average infusion time was 0.95 hours (range 0.2-6.4 hours) and most (84.9%) used 1 to 2 needlesticks.

[§] You'll infuse your first 2 infusions at 10 to 20 mL/hr/site. After that, you'll be able to increase your rate up to 60 mL/hr/site as tolerated. Infuse at up to 4 sites simultaneously.

SubQ IG=subcutaneous immune globulin.

IMPORTANT SAFETY INFORMATION (continued)

- 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 sign of an infection.

The following one or more possible side effects may occur at the site of infusion. These generally go away within a few hours, and are less likely after the first few infusions.

- Mild or moderate pain
- Redness
- Itching

The most common side effects that may occur are:

- Headache
- Nausea
- Fatigue
- Diarrhea
- Vomiting

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.

Please see Important Facts about CUVITRU on the following page.

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

Register for a community educational program created for people living with PI—*My Life, My Story.*

Learn more about what it's like to infuse CUVITRU from clinical nurse educators and other patients like you.

IMPORTANT FACTS about CUVITRU (CUE-vih-troo) [Immune Globulin Subcutaneous (Human)] 20% Solution

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

CUVITRU can cause the following serious reactions:

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

What is CUVITRU?

CUVITRU is a ready-to-use liquid medicine that contains immunoglobulin G (IgG) antibodies, which protect the body against infection. CUVITRU is used to treat patients with primary immunodeficiency diseases (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. CUVITRU is made from human plasma that is donated by healthy people. CUVITRU contains antibodies collected from these healthy people that replace the missing antibodies in PI patients.

Who should not use CUVITRU?

Do not use CUVITRU if you have a known history of a severe allergic reaction to immune globulin or other blood products. If you have such a history, discuss this with your healthcare provider (HCP) to determine if CUVITRU can be given to you. Tell your HCP if you have a condition called selective (or severe) immunoglobulin A (IgA) deficiency.

How should I use CUVITRU?

CUVITRU is given under the skin (subcutaneously). Most of the time, infusions under the skin are given at home by self-infusion or by caregivers. Instructions for giving CUVITRU under the skin (subcutaneously) are provided in the FDA-approved patient labeling (Information for Patients and Instructions for Use). Only use CUVITRU by yourself after you have been instructed by your HCP.

What should I avoid while taking CUVITRU?

CUVITRU 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 CUVITRU.

Tell your HCP if you are pregnant, or plan to become pregnant, or if you are nursing.

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

The following are one or more possible reactions that may occur at the site of infusion. These generally go away within a few hours, and are less likely after the first few infusions.

- Mild or moderate pain
- Redness
- Itching

The most common side effects of CUVITRU are headache, nausea, fatigue, diarrhea, and vomiting.

If any of the following problems occur after starting treatment with CUVITRU, stop the infusion immediately and contact your HCP or call emergency services. These could be signs of a serious problem.

- 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 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.

These are not all the possible side effects. You can ask your HCP for a physician's information leaflet. Tell your HCP about any side effect that bothers you or that does not go away.

Whenever giving yourself treatments at home, you should have another responsible person present to help treat side effects or get help if you have a serious adverse reaction occur. Ask your HCP whether you should have rescue medications, such as antihistamines or epinephrine.

How do I store CUVITRU?

Store CUVITRU refrigerated or at room temperature.

- You can store CUVITRU in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 36 months or
- You can store CUVITRU at room temperature (up to 77°F [25°C]) for up to 24 months.
- Do not return CUVITRU to the refrigerator if you take it out to room temperature.
- Do not freeze.
- Do not shake.
- Check the expiration date on the carton and vial label. Do not use CUVITRU after the expiration date.
- Protect from light. You can use the original CUVITRU containers to protect it from light.

How do I get more information about CUVITRU?

The risk information provided here is not comprehensive. To learn more, talk about CUVITRU with your HCP or pharmacist. The FDA-approved Full Prescribing Information, including Information for Patients, can be found at www.CUVITRU.com or by calling 1-877-TAKEDA7 (1-877-825-3327).

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Remote monitoring tools. Remote patient monitoring (RPM) involves using connected electronic devices to record personal health and medical data in one location for review by a provider at a different location. These devices assist clinical decision-making by analyzing vital health data points and generating alerts. When coupled with AI, this approach can potentially reduce costs by optimizing hospitalization and avoiding complications.

AI-powered RPM may achieve better health outcomes and lower expenses through early detection of adverse health events and prioritizing hospitalization. The quality of care increases, especially with continuous RPM because it lowers the chance of further complications and readmission. However, continuous monitoring produces a large amount of clinical data, making it impossible to analyze without an AI algorithm.

AI-enabled wearable devices. Integrating AI with wearable health devices has transformed how patients and providers monitor and manage health. These electronic companions have evolved beyond simple fitness trackers to become indispensable tools for holistic well-being and chronic disease management. For medical experts, they provide important information that can inform diagnoses and treatment, as well as monitor progress related to ongoing conditions.

AI-enabled wearables offer real-time data and continuous monitoring of health indicators, informing and enhancing strategies to manage chronic conditions. Some innovative examples include:

- Lumen: A metabolic measurement device that analyzes breath composition to provide personalized nutrition and fitness recommendations
- Spire Health Tag: A tracking device that focuses on stress management by monitoring breathing patterns and heart rate variability
- Biostrap: A holistic fitness tracking device that combines heart rate, oxygen saturation and movement tracking
- Oura Ring: A comprehensive health and wellness device that tracks sleep patterns, heart rate, body temperature and activity levels to provide personalized insights into overall health and daily readiness

Real-time health data analysis. AI algorithms are like smart helpers in analyzing the large amounts of health data collected from wearable devices. These devices track vital signs such as heart rate, blood pressure, respirations and much more. By processing this information, AI can establish a personalized baseline for patients, considering their age, gender, medical history and current health status.

The real-time analysis provided by AI offers several benefits:

With AI, patients may experience more timely interventions and a healthcare experience explicitly tailored to their needs.

- Continuous monitoring: AI-equipped devices continuously gather data, ensuring health information is always current. This means doctors can have constant information about their patients' health.
- Pattern recognition: AI is very good at spotting patterns in data such as irregular heart rhythms, sudden changes in blood pressure or unexpected shifts in activity levels. This helps quickly identify potential health issues.
- Anomaly detection: AI can detect unusual changes in health data that fall outside what is considered normal for a patient, alerting healthcare providers to intervene promptly if necessary.
- Predictive analysis: AI not only detects current issues but can also predict potential health problems by analyzing trends in historical data. This means potential health risks can be addressed before they become serious.

By utilizing these AI capabilities, healthcare providers can offer more personalized and proactive care, improving health outcomes and making healthcare delivery more efficient. With AI, patients may experience more timely interventions and a healthcare experience explicitly tailored to their needs.

AI-Driven Clinical Decision Support Systems

AI-driven clinical decision support systems (CDSS) are transforming healthcare by providing doctors with real-time, evidence-based recommendations. These systems help healthcare providers make better decisions and improve

patient outcomes using advanced technologies that work with existing healthcare tools.

Integration with electronic health records (EHRs). AI-powered CDSS work seamlessly with EHRs to access and analyze patient health information. This means the system can look at a lot of data such as medical history, lab results and medication records to give doctors a clear picture of patients' health. Using unique software platforms, these systems easily integrate with EHRs, allowing healthcare providers to make well-informed decisions based on comprehensive health information.

Evidence-based treatment suggestions. AI-driven CDSS offer treatment suggestions by analyzing health data and clinical guidelines. For example, if a patient has an autoimmune disorder or a PI, the system can provide personalized treatment recommendations based on the patient's medical history and current medications. It can help doctors choose the best treatment options for patients, considering how different medications might interact and how likely they are to work based on patients' unique health profiles. This personalized approach helps ensure patients receive the most effective and safe treatments, potentially reducing trial and error in medication management.

Medication management assistance. AI systems also help manage medications by optimizing prescriptions and improving how well patients follow their treatment plan. They can prioritize medications covered by insurance, check for possible drug interactions and alert doctors to important issues such as abnormal lab results or potential side effects.

In cases of autoimmune disorders, AI can help track medication adherence and analyze how it affects patients' overall health. This can lead to better management of patients' conditions and potentially reduce the need for hospital visits. AI can also predict flare-ups by monitoring subtle changes in health data, allowing for early intervention. Using AI's ability to analyze data and predict outcomes, CDSS can significantly enhance patients' care and support their healthcare providers in making informed decisions about treatment. As these systems continue to evolve, they will play an even more vital role in helping patients manage chronic diseases effectively, offering a proactive approach to healthcare.

Challenges and Ethical Considerations

Data privacy and security. As AI becomes more integrated into healthcare, keeping patients' health data private and secure has become a significant concern. With the growing use of digital health records, there is a risk that personal health information could be misused or that patients could be identified from these large data sets. Even when data is de-identified (stripped of personal details) before being shared, the risk of someone figuring out who a patient is remains a concern. Breaches in privacy can have serious consequences. Tangible effects might include workplace discrimination or higher insurance premiums if a patient's medical history is exposed. On the other hand, the loss of privacy can also make patients feel like they've lost control over their personal information, which is a concern.

Algorithm bias and fairness. AI systems in healthcare can sometimes be biased because of the data from which they learn. This can happen if the data includes historical inequalities or lacks information about certain groups of people. When AI learns from biased data, it can end up making less accurate recommendations for racial minorities, women, low-income individuals and other underrepresented groups. For example, if an AI tool has been primarily trained on data from one demographic, it might not work as well for others. Ensuring AI systems are fair and inclusive is essential to prevent these biases and to offer everyone equal quality of care.

Patient trust and acceptance. Using AI in healthcare also faces challenges around building trust and acceptance. Changes can sometimes be met with skepticism, both from patients and healthcare providers. Many naturally resist new technologies in favor of what they are used to. For healthcare professionals, there are concerns about who is responsible if AI makes a mistake. There are also fears that AI might replace human jobs, although the goal is to support and enhance the work of healthcare providers, not replace them. The healthcare industry must adhere to high ethical standards and implement strong safeguards to address these challenges. Being open and transparent about how AI tools work, how they use data and what they are designed to do can help build trust. By tackling these challenges head-on, we can move toward a more fair and effective use of AI in managing health conditions.

Changing How Healthcare Is Delivered

Integrating AI in managing chronic diseases can change how healthcare is delivered and improve patient outcomes. Using predictive analytics, AI can help identify health issues before they become serious. This technology supports doctors by providing real-time data and personalized care strategies, making treatments more effective and improving the quality of life for people with long-term conditions. AI helps healthcare providers identify potential problems early, tailor interventions specifically to individual needs and optimize medication plans, making managing diseases more effective and reducing healthcare costs.

While AI can potentially enhance healthcare, it is important to consider its benefits and challenges. On the positive side, AI can assist healthcare providers in diagnosing conditions more quickly and accurately, tailoring treatments to individual needs and monitoring patient health in real-time. These capabilities can improve healthcare outcomes and contribute to more personalized care.

However, challenges and ethical considerations also need to be addressed. Ensuring data privacy and security is a significant concern, as personal health information must be protected from misuse. It is also essential to ensure AI systems are fair and unbiased, since biases in AI algorithms can lead to unequal treatment or misdiagnosis for certain groups of patients. Building trust with patients is crucial for successfully integrating AI into healthcare, and this requires transparency about how AI technologies work and how they use patient data.

Patients should be informed about how AI might impact their healthcare and discuss these technologies with their healthcare providers. By staying informed and engaged, patients can play an active role in their healthcare decisions and make the most of modern medical advancements. While AI offers promising possibilities, a careful and balanced approach is necessary to harness its full potential responsibly. IG

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Too Bizarre to Be True:

Social Media's Viral (and Hazardous) Health Trends

While many health claims abound on the Internet, if it sounds to good to be true, it probably is.

By Rachel Maier, MS

SOCIAL MEDIA can be a fun tool for people to connect, share and learn, but it can be a frustrating tool that causes confusion, harm and even medical emergencies. Sorting through the wheat and chaff of reliable posts — especially when it comes to health and wellness topics — can be tough.

This is especially true in our culture that is constantly looking for a quick fix. If we are honest, we don't really like putting in the time or effort required for real and lasting improvements in our health and wellness, so we are vulnerable to lofty promises. Illogical, outlandish health claims appeal to us. As long as a "new" health trend promises to make us look younger, feel better or live longer, we are willing to try it.

True, some trends are harmless and healthy, such as eating "nature's cereal" (a bowl of fruit drizzled with coconut water) or "exercise snacking" (fitting mini-workouts into your busy day), but some trends are harmful and hazardous, such as "dry scooping" (swallowing a scoop of dry protein powder before a workout) or using pure hydrogen peroxide to whiten your teeth at home. Recognizing which is which is often easy and obvious, but sometimes it can be really tricky.

Online Access to Health Information

For better or worse, people have been seeking out medical information online. Twenty years ago, before social media really took off, more than 80 percent of Americans were already turning to the Internet for health information. In fact, according to a survey conducted by the Pew Research Center, searching for health information online was more popular than using email at the time. People searched for health information on a handful of legitimate websites and found credible information that was hard to understand, detached and impersonal.[2]

Since then, social media shook things up. Not only did it make health information even more accessible online, it also made it easier to understand. By 2024, an astounding 87 percent of millennials and Gen Z turned to social media for nutrition and health advice, according to a survey conducted by MyFitnessPal.[3]

Some health information is credible: Physicians, nurses and other healthcare professionals increasingly took to platforms such as Instagram, Facebook and TikTok to communicate important health information to patients in personable, plain language. The problem is, experts aren't the only ones sharing health information online. Regular people are popping up all over the Internet sharing their personal health stories, and many are influencing millions of people in the process (which is why so many of them are dubbed "influencers"). Their personality, success stories and the perception of personal connection keeps followers coming back. While some influencers altruistically share anecdotes along with accurate medical information, many more are peddling outlandish and dangerous health claims experts are feverishly (and perhaps somewhat futilely) refuting.

Trustworthy or Tricky?

For social media users, this creates a conundrum: Who and what do I believe? On one hand, influencers can be relatable, regular folks who are not only easy to understand but also engaging and inspiring. Emotions play a big role in users' receptiveness to or trust in the information shared. People want a quick fix, a miracle cure, an easy out or a secret method, and they seem to think they get a better understanding of how medical conditions, treatments and maintenance actually work from regular people like themselves. On the other hand, trained, credentialed medical professionals sometimes contradict the "miracle" stories relayed by influencers. Because users can share posts, inaccurate information wrapped in a compelling story can catch on fast (and thus be considered "trending content"), and before you know it, questionable content is trending, and figuring out whether it is reliable gets harder.

> **Health trends are touted as novel life-changing tips and tricks, but they are generally an old idea packaged a new way.**

Old Ideas in New Packages

Health trends are touted as novel life-changing tips and tricks, but they are generally an old idea packaged a new way. Take the liquid chlorophyll trend for example. This social media trend touts the benefits of adding a few drops of liquid chlorophyll to water, juice or smoothies to guard against cancer, heal wounds, diminish acne, control body odor, boost energy, relieve constipation and gas, reduce fine lines and wrinkles and even lose weight.[4] However, humans have been reaping the benefits of chlorophyll for eons, since it is a natural component of green, leafy vegetables, and we have plenty of studies showing the benefits of eating those. (We don't have much evidence that consuming liquid chlorophyll is any more beneficial to humans than prioritizing eating our vegetables.)

Another example is the hormone balancing craze. Search #hormonebalancing on TikTok and you will find a slew of strategies for balancing hormones naturally, including regularly eating raw carrot salad to prevent producing extra estrogen. However, while eating raw carrots does have health benefits, there just isn't research to back up the trending health claim that regularly consuming them has any effect on estrogen levels in the body.[5] Following are eight more trends to approach with caution.

1) *Nutritional supplement diffusers.* Also known as wellness vapes, vitamin vapes or healthy vapes, so-called "nutritional supplement diffusers" allow users to inhale good-for-you ingredients without nicotine. These devices are slim, colorful and similar to electronic cigarettes, but are pushed as vitamin-infused formulas that are a "healthy" alternative to nicotine vapes.[6] Wellness vapes work the same way nicotine vapes work: Batteries emit enough energy to heat up the liquid inside, turning it into vapor that the user inhales.

Wellness vapes claim to deliver health benefits and offer a variety of inhalable options such as vitamin B12 and caffeine to increase energy; melatonin to soothe and support sleep; essential oils such as lavender and chamomile to help relax; and vitamin C and other essential vitamins to support overall wellness goals. The idea is that breathing supplements into the lungs may speed up the rate of absorption into the bloodstream, which means users are more likely to feel the effects faster.[7]

However, there have not been sufficient studies on the effects of inhaling these substances, let alone the flavorings or propellants that are also used in them, and a preliminary study suggests they may actually cause cell damage. And, these products are not approved by the U.S. Food and Drug Administration (FDA). "The U.S. FDA has warned consumers in the U.S. that wellness vapes could actually have adverse effects, outweighing any nutritional or emotional

benefits.”[7] It can cause severe coughing and/or airway tightening, which can make breathing and speaking difficult. For those interested in upping their supplement game, it’s best to stick to taking FDA-approved products.

2) *Mouth taping.* The idea behind this trend is simple: Tape your mouth shut to force your body to breathe through your nose while you sleep. Enthusiasts use a special adhesive such as medical tape or even specially made “mouth tape” that will keep lips shut all night, thus preventing mouth breathing overnight and allegedly helping them sleep better.

While there are negative effects associated with mouth breathing (bad breath; daytime fatigue or tiredness; dry mouth; poor oral health, including cavities and gum disease; reduced mental skills, especially working memory; symptoms related to attention deficit hyperactivity disorder; sleep disordered breathing, including sleep apnea; slowed growth in children) and positive effects associated with nose breathing (overnight nose breathing helps regulate air temperature, filters allergens, debris and other toxins out of the air, and keeps your mouth and throat moist), this method has not been studied enough to prove its safety or effectiveness.[8]

Toni Golen, MD, editor in chief, and Hope Ricciotti, MD, editor at large of *Harvard Women’s Health Watch*, respectively, caution against mouth taping. “While intentional nose breathing during waking hours can offer many benefits — including slowing breathing, filtering allergens and easing anxiety — taping your mouth while sleeping to achieve this can prove risky, leading to hampered breathing, disrupted sleep or skin irritation. There’s no research to support the measure, which, in certain cases, could significantly reduce a person’s oxygen levels while sleeping.”[9] If you have trouble breathing through your nose on your own while you sleep, go talk to your doctor, who can help you determine whether you have a nasal obstruction, allergies, asthma or sleep apnea. Understanding why you are a mouth breather while you sleep will help you find a safe and proven solution to the problem.

3) *Ozempic imposters.* “Budget Ozempic” and “oat-zempic” are riffs on the wildly popular Ozempic, the injectable medication called semaglutide that mimics the hormone GLP-1, which helps the pancreas release insulin. Ozempic is FDA-approved for the treatment of diabetes but has recently been used off label for weight loss, culminating in the recent FDA approval of Wegovy (a version of Ozempic specifically approved for weight loss). However, these drugs are available by prescription only and can be extremely expensive. The surge in popularity made them scarce during the fall of 2023, and pharmacies struggled to keep up with the demand. During the shortage, and lured by the idea of a quick fix, people wanting to shed extra pounds turned to laxatives (most specifically Miralax), and social media posts pushing Miralax as “budget Ozempic” started trending on TikTok, so much so that Miralax ended up experiencing a shortage, too.

Another budget Ozempic trend is known as “oat-zempic,” an oat-based meal replacement beverage consisting of oats, lime juice, water and cinnamon. Replacing a meal with this concoction supposedly helps people lose weight.[10] But of course, neither of these substitutes work the same way semaglutide works for weight reduction.

While semaglutide slows down the movement of food through the stomach and curbs appetite, which can lead to weight loss, laxatives like Miralax purge the body of water, electrolytes and stool, which does not cause the body to lose body mass.[11] This may lead to dehydration, cramping, nausea, vomiting or low potassium levels in the blood, which can increase the risk of a heart attack. Regularly taking laxatives for issues other than constipation can also increase the risk of pancreatitis or kidney stones.[11] Meal replacement drinks are no better: They starve your body of the nutrients you actually need to be healthy. Neither result in lasting weight loss and can do more damage than good.

4) *Lemon coffee.* The lemon coffee trend is another weight-loss “quick fix” that promises a flatter belly and/or weight loss from simply drinking coffee with lemon juice every morning on an empty stomach. The idea is that the lemon juice burns fat, and combining it with coffee’s natural appetite-suppressing and metabolism-boosting properties helps shed unwanted pounds. However, according to registered dietitian

Some off-beat health trends won't hurt you, but they may not help you the way influencers claim they will. Still other trends are downright dangerous and shouldn't be attempted.

Beth Czerwony, RD, LD, the claim is unfounded. "That mechanism of action is just not there [...] There is nothing in lemon juice that is going to burn fat or a chemical connection to make that happen."[12] Further, lemons and coffee are both high in acid, and too much acid can cause heartburn, especially for people with a history of acid reflux. While lemon does offer nutritional value (it's high in vitamin C), Czerwony recommends staying away from this trend and getting your vitamin C elsewhere. She also emphasizes that if this was a magic bullet for weight loss, people would have been doing it for a long time.

5) *Bovine colostrum supplements.* You read that right: The milky liquid that female mammals first produce after giving birth and before milk comes in is being collected from cows, processed, packaged, sold and consumed by humans. Influencers insist it supports gut health, improves immunity, aids in muscle recovery and more. All mammals produce colostrum immediately after giving birth, specifically to give their newborns nutrients that boost and protect their young immune system. Colostrum is jam-packed with protein, essential fatty acids, antioxidants, antibodies and even immunoglobulins. While colostrum does not seem to pose a risk to humans (except for to those who are allergic to cow's milk), there is not enough evidence to prove its safety or efficacy, either.

"Further studies are needed, and more robust data collected, before a clear recommendation can be made on usage," said wellness dietitian Lindsey Wohlford, MS, RD, LD. It has not been approved by FDA either, so "standard formulations and regulations for production do not exist."[13] Doctors maintain that the best nutrition is still found in whole foods, not supplements. If you want to flood your body with nutrients, eat real food. Nutrients found in real, whole food are easier for the body to absorb than those found in supplements anyway.[13]

6) *Healthy coke.* So-called "healthy coke" is a mix of sparkling water and balsamic vinegar. The idea is to swap a sugary beverage for a bubbly drink that not only nixes the sugar and calories but also offers health benefits. Vinegar is low in calories; contains antioxidants called polyphenols that help combat oxidative stress; may enhance skin health; supports healthy weight maintenance by increasing satiety; promotes digestive health; lowers blood pressure; and improves blood sugar control.

Influencers who push healthy coke swear that while it does not taste like a regular cola beverage, it tricks their body into thinking it is, and that it is actually more palatable than it sounds. If taste alone doesn't deter you, consider this: While there are some health benefits to balsamic vinegar, overconsumption may damage tooth enamel and lead to acid reflux or heartburn.[14] Vinegar may also aggravate a peptic ulcer. Taking vinegar may cause your blood sugar levels to dip to dangerous levels, which can cause dizziness or fainting.[15] Anyone who wishes to add vinegar to their daily dietary routine should discuss the risks and benefits with their doctor prior to starting a new regimen.

7) *Garlic cloves in the nose.* Garlic has many health benefits, including boosting immunity and tamping down inflammation. The idea behind this trend is that putting a garlic clove in the nose is a quick and easy way to relieve nasal congestion associated with colds and allergies. When the garlic clove is removed, mucus comes pouring out. Raj Sindwani, MD, an otolaryngologist at the Cleveland Clinic, explains that happens because the garlic irritates the lining of the nose, which causes even more mucus to build up behind it. All the mucus is trapped until the clove is removed. What rushes out when the clove is removed is both the mucus you already had and the excess produced because of the irritant. However, he emphasizes that putting a garlic clove in the nose to relieve congestion is a dangerous idea. Not only could the clove get stuck, but it could also cause irritation, infection or injury. Instead of this "hack," stick to tried-and-true methods of hydration, saline irrigation and rest.[16]

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immune globulin injection (human), 10%
caprylate/chromatography purified

Step out of the symptoms of CIDP and back into your life with GAMUNEX-C

GAMUNEX-C blocks the autoimmune and inflammatory processes of CIDP, which may improve symptoms and protect your nerves from damage.[1-3]*

*The way in which GAMUNEX-C works in treatment of people with CIDP is not completely understood.

GAMUNEX®-C (immune globulin injection [human], 10% caprylate/chromatography purified) is approved to treat primary humoral immunodeficiency disease (PIDD) in patients 2 years of age and older. If you have PIDD, you may take GAMUNEX-C under the skin (subcutaneously) or in a vein (intravenously). GAMUNEX-C is also approved to treat idiopathic thrombocytopenic purpura (ITP) in adults and children and chronic inflammatory demyelinating polyneuropathy (CIDP) in adults. If you have ITP or CIDP, you may only take GAMUNEX-C intravenously.

Do not take GAMUNEX-C if you have an allergy to immune globulin. Tell your doctor if you have had a serious reaction to other medicines that contain human immune globulin. Also tell your doctor if you have immunoglobulin A (IgA) deficiency. If you have a serious reaction while taking GAMUNEX-C, stop taking it immediately and tell your doctor.

CIDP, chronic inflammatory demyelinating polyneuropathy.

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IMPORTANT SAFETY INFORMATION

GAMUNEX®-C (immune globulin injection [human], 10% caprylate/chromatography purified) is approved to treat primary humoral immunodeficiency disease (PIDD) in patients 2 years of age and older. If you have PIDD, you may take GAMUNEX-C under the skin (subcutaneously) or in a vein (intravenously). GAMUNEX-C is also approved to treat idiopathic thrombocytopenic purpura (ITP) in adults and children and chronic inflammatory demyelinating polyneuropathy (CIDP) in adults. If you have ITP or CIDP, you may only take GAMUNEX-C intravenously.

If you take GAMUNEX-C or a similar immune globulin product, you could experience a serious and life-threatening blood clot (thromboembolism), which 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. You are more likely to develop a blood clot if you have a history of hardening of the arteries (atherosclerosis), stroke, heart attack, or heart failure (low volume of blood pumped by the heart). You may also be more likely to get a blood clot if you are elderly, if you have a blood clotting disorder, if you are inactive for long periods of time (such as long bed rest), if you use estrogens, or if you have thickening of your blood. For patients at risk, GAMUNEX-C should be administered at the lowest dose and slowest infusion rate that is practical. However, blood clots may occur in the absence of any of the known risk factors. Patients should be well hydrated by drinking enough water before GAMUNEX-C is administered. Tell your doctor immediately if your medical history is similar to what is described here, and especially if you start having any of these symptoms while taking GAMUNEX-C.

If you take GAMUNEX-C or a similar immune globulin product intravenously, you could experience serious kidney disease and death. You may have symptoms of decreased urination, sudden weight gain, swelling in your legs (edema), or shortness of breath. You are more likely to develop serious kidney disease if you already have a kidney problem, have Type II diabetes mellitus, or are older than 65. You are more likely to develop serious kidney disease if you are dehydrated, have a blood infection (sepsis), have high protein content in your blood, or if you are receiving other medicines that are harmful to your kidneys. Tell your doctor immediately if your medical history is similar to what is described here, and especially if you start having any of these symptoms while taking GAMUNEX-C.

You are more likely to develop serious kidney disease if you take an intravenous immune globulin product that contains sugar (sucrose). GAMUNEX-C does not contain sugar. If your situation makes you more likely to experience serious kidney disease, you should take GAMUNEX-C at the lowest concentration available and the slowest infusion rate that is practical.

Do not take GAMUNEX-C if you have an allergy to immune globulin. Tell your doctor if you have had a serious reaction to other medicines that contain human immune globulin. Also tell your doctor if you have immunoglobulin A (IgA) deficiency. If you have a serious reaction while taking GAMUNEX-C, stop taking it immediately and tell your doctor.

Periodic monitoring of kidney function and urine output is particularly important in patients more likely to experience severe kidney disease.

You could experience other serious and life-threatening problems due to immune globulin. You could get aseptic meningitis (a type of brain inflammation with symptoms of severe headache, stiff neck, fatigue, fever, sensitivity to light, painful eye movements, nausea, and vomiting), a blood problem called hemolytic anemia (common symptoms include increased heart rate, fatigue, yellow skin or eyes, and dark-colored urine), and/or a lung problem called transfusion-related acute lung injury (commonly referred to as TRALI). TRALI is a condition where you build up fluid in the lungs (called pulmonary edema) that is not the result of heart failure.

If you have higher than normal body fluid volumes or if you have a condition where increasing body fluid volume may be a concern, a higher dose, such as 1g/kg for 1-2 days, is not recommended.

Because GAMUNEX-C 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.

You may not take GAMUNEX-C subcutaneously if you have ITP. **If you have ITP and take GAMUNEX-C subcutaneously, you could experience a very serious and life-threatening black and blue wound (hematoma, which is a pocket of blood within a tissue).**

After you take GAMUNEX-C, your blood antibody levels may rise, which could cause some blood antibody tests to give false results.

The most common side effects in a clinical study with PIDD patients who got subcutaneous injections of GAMUNEX-C were infusion-site reactions such as redness, swelling, and itching; extreme tiredness; pain in the region of the head or neck; a runny nose, nasal congestion, sneezing, cough, and sputum production; joint pain; loose stools; a sensation of unease and discomfort in the upper stomach; swelling of the tissue lining the sinuses; inflammation of the airways that carry air to your lungs; a feeling of unhappiness, sadness, melancholy, gloom, hopelessness, or low spirits; red rash or bumps, itchy, swollen, and tender skin with or without blisters or a burning feeling; a severe throbbing pain or a pulsing sensation, usually on just one side of the head; muscle pain; familiar infectious diseases such as the common cold or flu; and raised body temperature or fever. In clinical studies with PIDD patients who got GAMUNEX-C intravenously, the most common side effects were cough; irritation and inflammation of the mucous membrane inside the nose; sore throat caused by inflammation of the back of the throat; pain in the region of the head or neck; a condition in which your airways narrow and swell and produce extra mucus; a sensation of unease and discomfort in the upper stomach; raised body temperature or fever; loose stools; and swelling of the tissue lining the sinuses. In a clinical study with CIDP patients who got GAMUNEX-C intravenously, the most common side effects were pain in the region of the head or neck; raised body temperature or fever; abnormally high blood pressure; feelings of coldness accompanied by shivering; a noticeable change in the texture or color of your skin such as your skin becoming scaly, bumpy, itchy, or otherwise irritated; a sensation of unease and discomfort in the upper stomach; joint pain; and abnormal physical weakness or lack of energy. In clinical trials with ITP patients who got GAMUNEX-C intravenously, the most common side effects were pain in the region of the head or neck; a discoloration of the skin resulting from bleeding underneath, typically caused by bruising; vomiting, fever, nausea, rash, abdominal pain, back pain, and a pain or an uncomfortable feeling in the upper middle part of your stomach.

The most serious side effects in clinical studies were a blood clot to the lung (pulmonary embolism) in 1 patient with a history of this condition (in CIDP), a flare-up of an existing type of anemia (autoimmune pure red cell aplasia) in 1 patient (in PIDD), and heart inflammation (myocarditis) in 1 patient (in ITP).

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

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

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GAMUNEX®-C

Immune Globulin Injection (Human), 10% Caprylate/Chromatography Purified

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use GAMUNEX®-C safely and effectively. See full prescribing information for GAMUNEX-C.

GAMUNEX®-C, [Immune Globulin Injection (Human), 10% Caprylate/Chromatography Purified]

Initial U.S. Approval: 2003

WARNING: THROMBOSIS, RENAL DYSFUNCTION and ACUTE RENAL FAILURE

See full prescribing information for complete boxed warning.

- **Thrombosis may occur with immune globulin products, including GAMUNEX-C. 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 GAMUNEX-C 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.**
- **Renal dysfunction, acute renal failure, osmotic nephrosis, and death may occur with immune globulin intravenous (IGIV) products in predisposed patients.**
- **Renal dysfunction and acute renal failure occur more commonly in patients receiving IGIV products containing sucrose. GAMUNEX-C does not contain sucrose.**
- **For patients at risk of renal dysfunction or failure, administer GAMUNEX-C at the minimum concentration available and the minimum infusion rate practicable.**

INDICATIONS AND USAGE

GAMUNEX-C is an immune globulin injection (human), 10% liquid indicated for treatment of:

- Primary Humoral Immunodeficiency (PI) in patients 2 years of age and older
- Idiopathic Thrombocytopenic Purpura (ITP) in adults and children
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) in adults

DOSAGE AND ADMINISTRATION

Intravenous Administration Only: ITP and CIDP

Indication	Dose	Initial Infusion Rate	Maintenance Infusion Rate (if tolerated)
ITP	2 g/kg	1 mg/kg/min	8 mg/kg/min
CIDP	loading dose 2 g/kg maintenance dose 1 g/kg	2 mg/kg/min	8 mg/kg/min Every 3 weeks

- Ensure that patients with pre-existing renal insufficiency are not volume depleted; discontinue GAMUNEX-C if renal function deteriorates.
- For patients at risk of renal dysfunction or thrombosis, administer GAMUNEX-C at the minimum infusion rate practicable.

Intravenous or Subcutaneous Administration: PI

DO NOT ADMINISTER SUBCUTANEOUSLY FOR ITP PATIENTS

Route of Administration	Dose	Initial Infusion Rate	Maintenance Infusion Rate (if tolerated)
Intravenous (IV)	300-600 mg/kg	1 mg/kg/min	8 mg/kg/min Every 3 to 4 weeks
Subcutaneous (SC)	1.37 x current IV dose in grams/ IV dose interval in weeks	Adult:[†] 20 mL/hr/site Pediatric:[†] 10 mL/hr/site (< 25 kg) 15 mL/hr/site (≥ 25 kg)	Adult:[†] 20 mL/hr/site Pediatric:[†] 10 mL/hr/site (< 25 kg) 20 mL/hr/site (≥ 25 kg) Weekly

[†] Adults: use up to 8 infusion sites simultaneously; pediatric: use up to 6 infusion sites simultaneously; for all ages, ensure infusion sites are at least 2 inches (5 cm) apart.

DOSAGE FORMS AND STRENGTHS

GAMUNEX-C is a sterile solution for injection supplied in 1 g (10 mL), 2.5 g (25 mL), 5 g (50 mL), 10 g (100 mL), 20 g (200 mL), or 40 g (400 mL) single use vials.

CONTRAINDICATIONS

- Anaphylactic or severe systemic reactions to human immunoglobulin
- IgA deficient patients with antibodies against IgA and a history of hypersensitivity

WARNINGS AND PRECAUTIONS

- IgA deficient patients with antibodies against IgA are at greater risk of developing severe hypersensitivity and anaphylactic reactions. Have epinephrine available immediately to treat any acute severe hypersensitivity reactions.
- Hyperproteinemia, with resultant changes in serum viscosity and electrolyte imbalances may occur in patients receiving IGIV therapy.
- Aseptic Meningitis Syndrome (AMS) may occur, especially with high doses or rapid infusion.
- Hemolysis, either intravascular or due to enhanced RBC sequestration, can develop subsequent to GAMUNEX-C treatments. Risk factors include high doses and non-O blood group. Closely monitor patients for hemolysis and hemolytic anemia, especially in patients with pre-existing anemia and/or cardiovascular or pulmonary compromise.
- Monitor patients for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).
- Volume overload.
- GAMUNEX-C is made from human plasma and may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.
- GAMUNEX-C is not approved for subcutaneous use in ITP patients. Due to a potential risk of hematoma formation, do not administer GAMUNEX-C subcutaneously in patients with ITP.
- Passive transfer of antibodies may confound serologic testing.

ADVERSE REACTIONS

The most common adverse reactions observed in ≥ 5% patients were:

PI: Intravenous: Cough increased, rhinitis, pharyngitis, headache, asthma, nausea, fever, diarrhea, and sinusitis.

Subcutaneous: Local infusion site reactions, fatigue, headache, upper respiratory tract infection, arthralgia, diarrhea, nausea, sinusitis, bronchitis, depression, allergic dermatitis, erythema, migraine, myalgia, viral infection, and pyrexia.

ITP: Headache, ecchymosis, vomiting, fever, nausea, rash, abdominal pain, back pain, and dyspepsia.

CIDP: Headache, pyrexia, hypertension, chills, rash, nausea, arthralgia, and asthenia.

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

DRUG INTERACTIONS

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

USE IN SPECIFIC POPULATIONS

- Geriatric: In patients over 65 years of age do not exceed the recommended dose, and infuse GAMUNEX-C at the minimum infusion rate practicable.

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8) *Shadow work.* For those who grapple with anxiety or depression, the idea of "shadow work" is alluring. It seeks to help people identify and work through subconscious patterns and trauma that may help explain or address their mental health struggles. While some attribute the idea of shadow work to psychiatrist Carl Jung, the TikTok trend was spurred by *The Shadow Work Journal,* a self-help workbook that was published by a 24-year-old without advanced training in clinical psychology.[17] The workbook guides users to delve deep into the shadowy places of their mind, including thought experiments imagining parental rejection and journal exercises recalling a misunderstood talent that was neglected, among other things.

According to Roger Bretherton, an associate professor of psychology at the University of Lincoln, Nebraska, thinking through hard parts of our lives can be helpful, but the solitary nature of shadow work can be dangerous because it digs deep into the subconscious and may reveal trauma. We need someone else to come alongside us as we do the hard work of confronting our past. "The problem with shadow work arises when we run into powerful emotions that completely take us over. Even without a traumatic personal history, it is possible to run into feelings of shame, rage and terror that so overwhelm us we have no capacity left to think about them. At such times, when we can't think, we need other people to do the thinking for us," he says.[18]

Sorting It All Out

As it turns out, when influencers — regular people who claim to have had success with the ideas they promote — tout a strange-sounding health or wellness hack, followers listen. Some off-beat health trends won't hurt you (eating raw carrot salad might not affect your hormones, but it is perfectly safe to eat), but they may not help you the way influencers claim they will. Still other trends are downright dangerous and shouldn't be attempted. Discerning which is which can be overwhelming, but applying the SIFT method may be helpful. The SIFT method was developed by digital literacy expert Mike Caulfield to help Internet users discern whether content found online is credible and trustworthy.[19] Here are four steps to take when considering a health claim found online:

1) *Stop*. Think about your initial response to the health claim and ask yourself: Does it elicit a strong emotional response? Does it seem too good to be true? What do you already know about what is being said?

2) *Investigate the source*. Find out a little bit more about the person making the health claim. Is that person an expert in that field? Does he or she have credentials? Is this a personal testimony? What is the goal of that person sharing the information? Is it a paid promotion, or is the personal otherwise incentivized to share it? Is the person's opinion biased?

3) *Find more coverage*. Do a little more digging and find other people talking about the trend, both those who support it and those who refute it. What do those sources say? Are major healthcare institutions recommending the same thing? Do some fact checking to see if they are supported by evidence. Try FactCheck.org and Snopes.com.

4) *Trace claims to their original source*. If references are cited, go back to those sources and read about the claim in context. Was the health claim accurately interpreted, quoted or represented? Does the trend support the original claims in the research? Is the supporting information cherry-picked to support the influencer's agenda or a bias?

Remember, the best way to confirm or refute wild health claims is to ask a trained, licensed healthcare provider about it. Talk to your doctor before you try anything that seems like it's too good (or bizarre) to be true, especially if you have underlying health conditions that could be affected by the trend.

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

Medicare Terms You Need to Know

Understanding the types of Medicare plans and common terms used in them will help ensure you get the treatment, medications and coverage you need.

By Abbie Cornett, MBA

RECENTLY, A GOOD friend of mine — one of the healthiest people I know — called me in a complete panic. She was applying for Medicare for the first time. Even though she's in great health, trying to navigate the maze of Medicare options left her stressed and confused, and she was overwhelmed by the required paperwork and all the different terms. As we talked, I started thinking about how much more complicated this process must be for people with chronic illnesses. For those with complex medical needs, understanding Medicare policies and jargon is not only important, it's critical for ensuring proper coverage.

When transitioning to Medicare, patients with chronic diseases such as immune deficiencies and autoimmune disorders treated with immune globulin (IG) therapy (either intravenous IG [IVIG] or subcutaneous IG [SCIG]) must know Medicare plans and policies — and also understand what they mean — to secure the best care and avoid unnecessary expenses. Careful planning is key. A mistake in coverage choice can directly affect your access to treatments, cost of medications and flexibility of care.

Breaking Down the Five Parts of Medicare

First, "Medicare" isn't one single plan. Medicare is divided into five parts, each covering a different aspect of healthcare: Part A (hospital insurance); Part B (medical insurance); Part C (Medicare Advantage); Part D (prescription drug coverage); and Medicare Supplemental Insurance ("Medigap"). Understanding each part and what it covers can be overwhelming if you are new to the system, but it is key to selecting the right coverage to meet your specific healthcare needs, including medications and treatments.

Knowing that Medicare isn't a "one-size-fits-all" program is crucial because choosing the wrong plan could result in gaps in care or higher out-of-pocket expenses.[1] By understanding the five parts of Medicare and how they work together, you can make informed decisions about your coverage. Whether you require hospital care, regular doctor visits, specialized treatments or prescription coverage, there's a Medicare plan or combination of plans that can meet those needs.

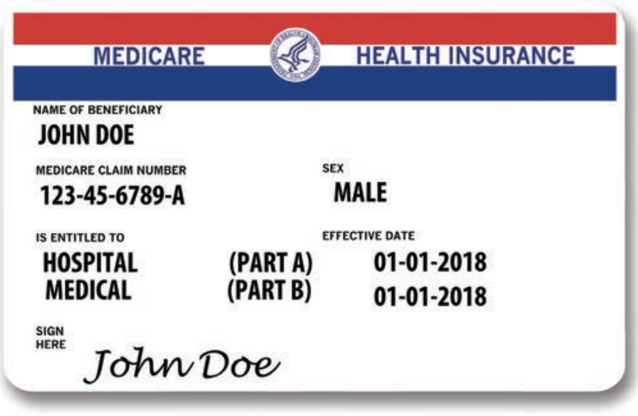
Medicare Part A: Hospital Insurance. When applying for Medicare, you will automatically be enrolled in Part A. Medicare Part A is a fundamental part of the Medicare program, primarily covering services related to inpatient hospital stays.[2] Coverage includes hospital care and stays in skilled nursing facilities, hospice care and some home healthcare services. Medicare Part A is often premium-free, provided you or your spouse paid Medicare taxes for a sufficient period during your working years. Those who haven't met the required Medicare tax period may need to pay a monthly premium.

Medicare Part A is important for individuals with chronic illnesses requiring frequent hospitalizations. Patients with immune deficiencies or long-term health issues often face multiple hospital stays, making it essential to understand what services Part A covers.

However, it's important to recognize that Part A has limitations. For example, skilled nursing facility care is covered only under certain conditions, and the duration of coverage may be capped. Knowing about these limitations helps you and your caregivers plan for any potential gaps in coverage and avoid unexpected costs or surprises.[3]

Medicare Part B: Medical Insurance. Medicare Part B complements Part A by covering outpatient services such as doctor visits, diagnostic tests, medical supplies and preventive care.[4] Part B is important for patients with chronic conditions because it provides coverage for regular medical appointments and treatments outside the hospital. This ongoing care is crucial for managing chronic illnesses because it allows patients to access specialists, receive diagnostic tests and obtain necessary treatments, without facing the financial burden of frequent visits. Additionally, Part B covers certain medical supplies patients may need such as durable medical equipment, which is especially beneficial for those managing long-term conditions at home.

One of Medicare Part B's unique aspects is its coverage



MEDICARE HEALTH INSURANCE

NAME OF BENEFICIARY
JOHN DOE

MEDICARE CLAIM NUMBER
123-45-6789-A

SEX
MALE

IS ENTITLED TO
EFFECTIVE DATE
HOSPITAL (PART A) 01-01-2018
MEDICAL (PART B) 01-01-2018

SIGN HERE
John Doe

of specific treatments, including IVIG therapy. Under Medicare Part B, this therapy is often covered when administered in a medical office, outpatient facility or clinic, making it easier for patients to receive their essential treatments in a clinical setting without worrying about exorbitant out-of-pocket costs.

Medicare Part B comes with a monthly premium, deductible and coinsurance. These premiums must be paid in addition to any premiums for Part A. Premium amounts vary based on income and are determined yearly according to the Social Security Act provision.[5] Part B coverage is vital for managing ongoing healthcare needs. Beyond regular treatments, it also covers preventive services such as screenings, vaccinations and annual wellness visits, helping you stay on top of your health and potentially preventing more severe health issues. It's important to note, however, that Part B only covers 80 percent of costs, leaving you responsible for the remaining 20 percent. So, without a Medicare Supplemental plan, you would be responsible for paying that 20 percent.

Understanding the full scope of what Part B offers helps you plan your care more effectively, ensuring you can access the services and treatments necessary to maintain your quality of life.

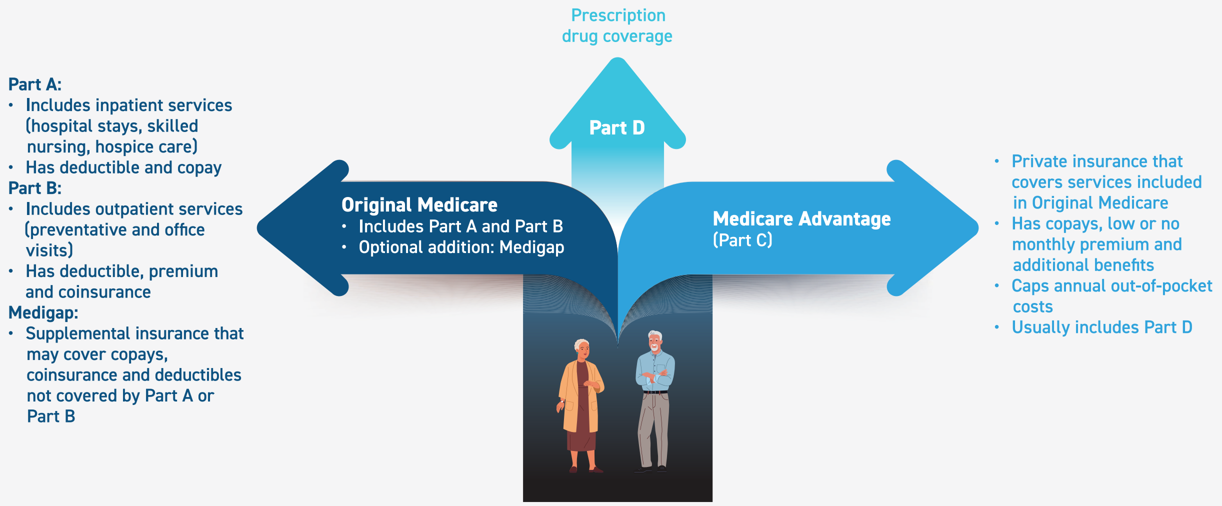
Medicare Part C: Medicare Advantage. Medicare Advantage, or Part C, is an optional private insurance alternative to Original Medicare (Parts A and B) that bundles hospital and medical coverage, often with additional benefits such as vision, dental and prescription drug coverage. Private companies approved by Medicare offer these plans, providing a more comprehensive package for some patients.

One of the appealing aspects of Medicare Advantage is the potential for extra benefits not typically covered under Original Medicare, such as fitness programs, wellness services or reduced prescription drug costs. However, coverage can vary significantly from one plan to another, and the specific benefits provided are at the discretion of private insurers.

If you are a patient with chronic illness(es), it's essential for you to carefully examine Medicare Advantage plans before enrolling. While some plans may offer broader coverage, others may impose strict limits on certain therapies or require prior authorization for treatments, potentially leading to delays in receiving necessary care or unexpected out-of-pocket costs. Additionally, you must ensure your preferred healthcare providers and specialists are included in the plan's network because Medicare Advantage plans often have more restricted provider networks.

Medicare Part D: Prescription Drug Coverage. Medicare Part D offers essential coverage for prescription medications,

Parts of Medicare and What They Cover



Part A:
- Includes inpatient services (hospital stays, skilled nursing, hospice care)
- Has deductible and copay

Part B:
- Includes outpatient services (preventative and office visits)
- Has deductible, premium and coinsurance

Medigap:
- Supplemental insurance that may cover copays, coinsurance and deductibles not covered by Part A or Part B

Prescription drug coverage

Part D

Original Medicare
- Includes Part A and Part B
- Optional addition: Medigap

Medicare Advantage (Part C)

- Private insurance that covers services included in Original Medicare
- Has copays, low or no monthly premium and additional benefits
- Caps annual out-of-pocket costs
- Usually includes Part D

Formulary Tier System

Drug Tier	Types of Drugs Included	Patient Cost
Tier 1	Most generic drugs	Low copay
Tier 2	Common brand-name drugs Preferred brand-name drugs Some high-cost generic drugs	Medium copay
Tier 3	Non-preferred brand-name drugs	High copay
Tier 4	Unique or very high-cost drugs	Percentage of total drug cost (coinsurance)

Source: Medicare Made Clear. What Is a Tiered Formulary and What Does It Mean for Me? Accessed at www.uhc.com/news-articles/medicare-articles/what-is-a-tiered-formulary-and-what-does-it-mean-for-me.

including some self-administered IG therapies. Unlike Parts A and B, Part D is not automatic; you must actively select a plan that fits your medication needs.

Each Medicare Part D plan has its own formulary, so researching which drugs are covered is crucial to avoid high out-of-pocket costs or lack of coverage. Carefully compare plans and review them annually since formularies can change, affecting coverage for medications from year to year. This is particularly important if you rely on regular prescriptions such as IG therapy, which can be costly if not included in your plan's formulary.

Medicare Supplement Insurance: Medigap. Medicare Supplemental plans, also known as Medigap, can help fill the gaps between Parts A and B. Medigap helps cover out-of-pocket costs not covered by Original Medicare[6] such as copayments, coinsurance and deductibles. It's important to note that Supplemental plans only cover Medicare-approved services, so they will help only with covered services.

Sold by private insurers, Medigap can be beneficial for patients who need frequent medical visits or treatments by reducing the financial strain of ongoing care. Unlike Medicare Advantage, Medigap works alongside Original Medicare, allowing beneficiaries to choose any provider who accepts Medicare. However, Medigap does not include prescription drug coverage, so if you enroll in Medigap, you must also enroll in a separate Medicare Part D plan for prescription coverage.

A Medigap plan is helpful for those managing chronic conditions because it reduces expenses such as copays and coinsurance. However, Medigap is not available for those on Medicare Advantage, so weigh the benefits of both options based on your needs. Since Medigap policies vary by plan and state, reviewing and comparing options is necessary to ensure you have adequate coverage.[7]

Key Medicare Terms You Need to Know

In addition to understanding the five parts of Medicare, familiarize yourself with key terms commonly used in Medicare plans. These terms can significantly influence access to medications and treatments and affect coverage options and out-of-pocket expenses. Familiarize yourself with them to navigate your plan(s) more effectively so you receive the care you need.

Formulary. A formulary is the list of prescription drugs covered by a Medicare Part D plan and its associated copays. Each Part D plan has its own formulary and can vary significantly. Formularies are divided into tiers, with different cost-sharing levels depending on how the medication is classified. Drugs in lower tiers generally have lower copays and drugs in higher tiers generally have higher copays.

Reviewing the formulary before enrolling in a plan can help avoid unexpected medication costs. Selecting a plan with the wrong formulary could result in higher costs or, even worse, denial of coverage for critical medications. Carefully compare Part D plans based on your specific needs to confirm the plan's formulary covers the medications you need. If you require specific, specialized therapies such as IG, it's important to ensure they are included in the formulary of the plan you select.

Prior authorization. Prior authorization is the process through which healthcare providers must get approval from a Medicare plan before a specific treatment, medication or service is covered.[8] Prior authorization ensures the treatment is deemed medically necessary before the plan will agree to pay for it. For patients needing IVIG or SCIG therapies, doctors must provide documentation and/or justification for why the treatment is required. Without prior authorization, the plan may not cover the treatment, resulting in high out-of-pocket costs.

Step therapy. Step therapy is a type of prior authorization required by Medicare and other insurance plans. It requires patients to try one or more lower-cost medications before "stepping up" to a more expensive medication. Patients must complete step therapy before the plan will approve the more expensive prescribed treatment, often including IG therapies. The goal is to control costs by ensuring lower-cost alternatives are attempted first, but it can pose challenges for patients with specific medical needs.[9]

> **Prior authorization is the process through which healthcare providers must get approval from a Medicare plan before a specific treatment, medication or service is covered.**

For patients with chronic illnesses, step therapy can result in delays in accessing the most effective treatment. Even if a lower-cost drug is ineffective or causes side effects, you may still have to undergo this "step" process before your preferred or medically necessary treatment is approved. Knowing if your plan requires step therapy can help you and you doctors navigate the process and advocate for the best treatment.

Coinsurance. Coinsurance is the percentage of costs patients must pay after meeting their deductible. For instance, if Medicare covers 80 percent of a particular service or medication, patients are responsible for the remaining 20 percent. Coinsurance can represent a significant out-of-pocket expense for costly treatments such as IG therapy.[10] Understanding coinsurance obligations under Medicare plans is crucial for effectively budgeting and managing healthcare costs.[11]

Deductible. A deductible is the amount patients must pay out of pocket for healthcare services or medications before their Medicare plan starts covering the rest. Each part of Medicare — whether it's Part A, B or D — comes with its own deductible, and these amounts can change every year. For people with chronic conditions, meeting the deductible is usually unavoidable because of the regular care needed.

Catastrophic coverage. Catastrophic coverage in Medicare Part D is a protection feature that kicks in after a patient has spent a certain amount on medications. Once this threshold is met, patients pay significantly lower copayments or coinsurance for the rest of the year. For those on expensive therapies like IG, reaching catastrophic coverage can be a financial relief since it reduces the burden of high prescription costs.[8]

Choosing the Right Plans Are Crucial

As you prepare to transition to Medicare, it's important to understand both your current and future healthcare needs, focusing on the medications and treatments you are prescribed to manage your chronic conditions. Remember: Choosing the right Medicare plan is not a one-size-fits-all decision. Understanding your individual healthcare requirements ensures you select the plan that provides the best coverage for you.

Resources such as Medicare's Plan Finder can assist with comparing options, including Medicare Advantage, Part D and Medigap, based on your specific circumstances. This tool allows for a comprehensive evaluation of coverage options, costs and benefits. Additionally, consulting with a Medicare counselor or patient advocate can provide valuable assistance because these professionals offer advice tailored to your unique needs as a chronic illness patient.

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ABBIE CORNETT, MBA, is the patient advocate for *IG Living* magazine.

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.

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

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*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.

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.

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Distributed by Pfizer Labs, Division of Pfizer Inc.

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
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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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March 2022

Peripheral Neuropathy and the Importance of Foot Care

Maintaining healthy feet is important for everyone, but it's crucial for people with peripheral neuropathy.

By Stephanie Oexeman, DPM, AACFAS, DABPM

AS A PODIATRIST, one of the most important aspects of my patient care is educating individuals about peripheral neuropathy and its impact on foot health.

Peripheral neuropathy is a condition that arises when the peripheral nerves, which carry signals from the brain and spinal cord to the rest of the body, become damaged. Since the feet are located far from the heart and brain, they are often one of the first areas affected by this condition.

The feet serve as the foundation of mobility, and any issues with patients' health can have significant consequences on their quality of life. Healthy feet allow patients to stay active, maintain their independence and avoid the complications that often arise from untreated conditions. For patients with peripheral neuropathy, routine foot examinations with a podiatrist can help prevent serious issues such as foot deformities, infections, ulcers and even amputations. Many complications associated with peripheral neuropathy are preventable through early detection and proper foot care.

Types of Neuropathy

There are three primary types of peripheral neuropathy: sensory, motor and autonomic. Each of these types affects the feet differently, and understanding the differences can help patients identify early warning signs and seek treatment with their podiatrists in a timely manner.

Sensory neuropathy primarily impacts the nerves responsible for sensation, including touch, pain and temperature detection. When these nerves are compromised, patients may experience symptoms such as tingling, burning or numbness in the feet. The loss of feeling in the feet can be particularly dangerous. For example, a person might step on a sharp object or develop a blister from ill-fitting shoes without realizing it. Over time, these unnoticed injuries can develop into ulcers or become infected, leading to further complications such as possible amputation. Proper sensation is vital for protecting the feet, and any change in sensory function should be taken seriously.

Motor neuropathy, on the other hand, affects the nerves responsible for controlling the muscles in the feet and legs. When these nerves are damaged, patients may find their feet and legs feel weak or fatigued. They may also notice difficulty in performing simple movements such as lifting the foot or walking long distances. In more severe cases, motor neuropathy can lead to muscle atrophy or deformities such as hammertoes, foot contractures and drop foot. These foot deformities not only affect patients' mobility but also increase the risk of falls and injuries. Over time, this can lead to a reduction in their ability to remain active, making it essential to address motor neuropathy early on.

Autonomic neuropathy affects the nerves that control the body's automatic functions such as sweating and blood flow. Autonomic neuropathy can result in excessively dry skin due to a lack of moisture regulation. Dry, cracked skin is more prone to developing sores and fissures, which can be painful and become infected if left untreated. Additionally, the reduced blood flow associated with autonomic neuropathy impairs the body's natural ability to heal wounds. This means that even minor injuries can take much longer to heal and are at higher risk of infection, particularly in people with underlying conditions like diabetes or poor circulation.

When patients visit a podiatrist for a foot and ankle assessment, they can expect a comprehensive evaluation of their feet.

Regular Foot Care

When patients visit a podiatrist for a foot and ankle assessment, they can expect a comprehensive evaluation of their feet. The assessment will usually begin with a visual inspection of the skin and nails to identify any signs of dryness, cracks, infections or abnormal growths. The podiatrist will also examine the shape and structure of their feet, looking for deformities or abnormalities that could affect gait or balance. Sensation testing is a key part of the evaluation for patients with peripheral neuropathy. Tools such as monofilaments or tuning forks are used to assess how well they can feel light touches and vibrations in different parts of the foot. This helps identify any areas where sensation may be diminished. Additionally, circulation will be evaluated to ensure there is adequate blood flow to the feet. Poor circulation can delay healing and contribute to the development of ulcers, especially in patients with autonomic neuropathy.

One of the most important steps in managing peripheral neuropathy is taking control of foot health through daily self-exams and prevention. Daily foot care routines are essential for detecting issues before they become serious. Patients should first start by inspecting their feet each day. I often recommend patients use a handheld or telescoping mirror to assist with looking at the bottom of the feet. Patients should check for changes in skin color, texture and temperature and keep an eye out for cuts, blisters, pressure spots, calluses and swelling. Washing feet regularly and thoroughly drying them afterward, especially between the toes, can prevent fungal infections. Applying a moisturizer after washing can help keep the skin hydrated and help prevent cracking. However, patients should be careful to avoid applying lotion between the toes, as excess moisture in that area can lead to fungal growth.

Injury Prevention

In addition to regular foot care, it's important for patients to protect their feet from potential injuries. People with peripheral neuropathy should avoid walking barefoot, even indoors. The risk of stepping on something sharp or burning their feet on a hot surface is significantly higher when sensation is diminished. Wearing shoes with proper support and coverage can help prevent accidental injuries. Furthermore, if patients notice any sores, blisters or cuts that are not healing as expected, they should contact their podiatrist immediately. Prompt treatment can prevent these minor issues from becoming more serious complications.

The role of proper footwear cannot be overstated when it comes to foot health, especially for patients with peripheral neuropathy. Wearing shoes that fit well and provide adequate cushioning and support is key to preventing foot problems.

- *Proper fit*. When selecting footwear, it is important to ensure that the shoes fit properly. Ill-fitting shoes can cause blisters, calluses and pressure points, which can easily lead to infections if they are not addressed promptly. Shoes that are too tight can restrict blood flow, while shoes that are too loose may not provide enough stability, increasing the risk of falls. Patients should always have their feet measured when purchasing new shoes, because foot size and shape can change over time, particularly in patients with neuropathy.
- *Orthotics and braces*. For patients with motor neuropathy or foot deformities, custom orthotics and braces may be necessary to provide additional support and alignment. Orthotics can help distribute weight evenly across the feet, reducing pressure on certain areas and helping to prevent injuries.
- *Socks*. Patients with autonomic neuropathy may benefit from moisture-wicking socks, which help keep the feet dry and reduce the risk of fungal infections.

If patients are unsure about the type of footwear that is best for them, they should consult with a podiatrist who can provide recommendations based on their specific needs.

Manage Symptoms and Minimize Risk

Peripheral neuropathy is a serious condition that requires diligent foot care to prevent complications. By staying proactive, regularly visiting a podiatrist and investing in proper footwear, patients can take control of their foot health and minimize the risks associated with neuropathy. Prevention is key, and with the right foot care routine, patients can continue to enjoy an active and independent lifestyle.

STEPHANIE OEXEMAN, DPM, AACFAS, DABPM, is a highly skilled and board-certified podiatric surgeon specializing in foot and ankle reconstructive and peripheral nerve surgery. She is the founder of Oexeman Foot and Ankle, PLLC, in Lincoln Park, Chicago.

Profile: Ilana Jacqueline

By Trudie Mitschang

ILANA JACQUELINE is author of the award-winning blog "Let's Feel Better" and a former columnist for *IG Living* magazine. She is also a health journalist and professional patient advocate whose work has included writing for publications such as *Cosmopolitan* and *The Huffington Post* on topics related to the patient experience. In addition, she has worked with healthcare companies and patient advocacy groups as a consultant and advisor. Her new book, *Medical Gaslighting: How to Get the Care You Deserve in a System that Makes You Fight for Your Life,* was published in October 2024, and unpacks the unfair treatment women face when navigating the healthcare landscape. She lives with her biochemist husband and what she describes as the cutest apricot poodle you've ever seen in Boca Raton, Fla.

Trudie: Can you briefly share your diagnosis story with our readers?

Ilana: Growing up with an undiagnosed immune deficiency meant constantly battling infections that never resolved with the same treatment that my peers received. It meant always feeling run down. Despite all the red flags, plentiful hospital admissions and multiple specialists, no one ever connected the dots. When I was 19, I finally encountered an infectious disease doctor who looked over my history and started running the right tests. Having a diagnosis of primary immune deficiency disease explained so much, but getting on the right treatment was another journey. It would be 10 years after my original diagnosis before I had an immunologist who knew how to help me manage my disease. At 30 years old, finally on consistent weekly subcutaneous immune globulin therapy, I experienced my first full year without an infection.

Trudie: For those who don't know, what is medical gaslighting?

Ilana: Medical gaslighting is the act of healthcare providers dismissing or ignoring patients' concerns or complaints and leaving them without a clear treatment plan or diagnosis, often stating that the patients have an unspecified mental illness or are exhibiting an unnecessary amount of caution.

Trudie: How common is this experience among patients in the chronic illness community?

Ilana: It's actually pretty common for patients with immune deficiencies to experience gaslighting throughout their diagnostic odyssey. I've enjoyed a 15-year career of interviewing patients with rare diseases and interviewing women with chronic illnesses in particular, and I've yet to come across even one patient who hasn't had some experience with being medically gaslit either on their way to becoming diagnosed or after diagnosis, and being questioned by other hospital staff or specialists about whether they were "really informed" about their diagnosis.

Trudie: What inspired you to write your book?

Ilana: You would think that after cementing a diagnosis, becoming an adult with a career in patient advocacy, and working with patients and physicians for so many years, that a doctor would not be able to gaslight me. But the reality is that to this day, I still encounter doctors who make the attempt. I knew, at some point, how to handle gaslighting in the exam room by having tried different tactics, but I wanted to know more. Why was I being gaslit? Who was teaching doctors to interact with patients this way? Was it just because I had a rare disease and a complex medical history, or did this happen to newly diagnosed patients with more common illnesses? I had a lot of questions and, for a few weeks, I considered turning that research into an editorial. But each time I was able to figure out the answer to one question, 10 more came in its place. I knew that the answers I really wanted were going to take time, effort and collaboration. To give the subject the in-depth investigation it deserved, I realized this was going to be a book.

Trudie: What has your research uncovered about the root cause of bias?

Ilana: There are so many factors that can cause a doctor to have a bias against you: It can be your age, your gender, your race, your profession, even just the color of your hair. And you can't always perfectly balance that power imbalance. But there are a few tricks like providing a witness, bringing in evidence of your condition such as symptom journals, and navigating the conversation calmly and confidently that can help you out in situations in which you can't access better care.

Trudie: Can you share a particular low point in your experiences with gaslighting?

Ilana: In one situation, I couldn't change doctors because no other providers in my area were accepting new patients. The provider I was seeing for pain management was openly hostile with me almost as soon as I walked into the room. He sneered at my explanations of pain and shamed me for not better managing my condition. He would get angry when I told him the treatments weren't working, that I was still having breakthrough pain. There was a clear power imbalance in the relationship, and I was scared to even bring up additional issues for fear he would lash out and I would be kicked out of the only open practice in my town.

Trudie: What "lessons learned" help you stand up for yourself during medical appointments today?

Ilana: All of my mistakes were really helpful in educating me on the best way to combat gaslighting. I like to think that my real research into this topic went back years. I sat down and analyzed all of my major encounters: What had I said? What had the doctor said? What evidence had I provided? What was I asking for help with? I started to record conversations in the exam room and listen to them — sometimes alone, and sometimes with my family to get their perspective on what went wrong. Some big takeaways were that I had to stick to the facts. It's hard to gaslight evidence: charts, symptom logs, blood tests. I also had to know when to end an appointment. Some doctors were not going to help me, and there really wasn't anything I could do or say to convince them to help me. Learning to leave a room that doesn't serve you was a radical realization.

Trudie: What support should readers seek if they are experiencing gaslighting?

Ilana: Support is important, and if readers have experienced medical gaslighting that leads to medical trauma, they should seek out a therapist with expertise in that area. However, more than just supporting or treating the aftermath of medical gaslighting, patients need to learn how to strategically fight back in a way that gets them the answers they need. This is the situation-by-situation playbook that covers responses to common phrases used when gaslighting a patient, how to understand when gaslighting has been notated in an electronic medical record, and how to refute it before it poisons the well with future members of your care team. There is a way to fight back that doesn't involve extreme confrontation, but instead gets doctors to admit their line of thinking isn't a reasonable response to the situation you're experiencing.

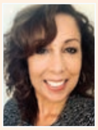
Trudie: Should patients hire a personal advocate?

Ilana: Shockingly to many who know me, I normally don't ever advise patients to do this. If the expectation of the patient looking to hire an advocate is that someone will become intimately familiar with your case, your medical history, your medications, your goals, your priorities, your allergies and the relationships already existing with your current providers — and then join you in the exam room for future appointments — it's going to cost you a fortune. Just to become acclimated to your case might require a minimum of six hours for an advocate who, if paid hourly, usually charges from $50 to $200 an hour. You will still have to be equally updated on your own case, present for all future appointments and, in the end, make the right decision for you on treatment.

Trudie: Are there other types of advocates that might be more affordable?

Ilana: Yes. There are still many opportunities to access different types of patient advocates who don't work on individual cases. For instance, your insurance company most likely has programs that have virtual advocates available to you at no cost. These advocates can call your doctor's office daily to work out issues with medication coverage, prior authorization and even appointment scheduling. Social workers can act as both therapists and advocates to your other healthcare providers, making calls on your behalf that might otherwise be ignored. Keep in mind that an advocate who works for your hospital may help you access different resources, set up appointments with outside providers, or even organize rides to and from appointments. But if you have an issue regarding the quality of your care, a hospital patient advocate is not going to advocate for you. They are paid by the hospital, and their job is to de-escalate conflicts and reduce the number of lawsuits brought to that hospital. If you suspect medical negligence or malpractice has taken place, you don't need an advocate. You need a lawyer.

Editor's note: Ilana's book Medical Gaslighting: How to Get the Care You Deserve in a System That Makes You Fight for Your Life *can be purchased on Amazon.com and wherever books are sold.*



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


iDF Immune Deficiency Foundation

It's OK to Say No

By Michelle Searle

DOES ANYONE else have a hard time saying no sometimes? It could be the people-pleaser in me, but it can be challenging to say no. Sometimes, we say no because we don't want to do something. Other times, we might *want* to say yes but can't because of health reasons or other obligations.

Recently, I've been seeing those reels on Instagram that say "no" is a complete sentence, meaning there is no need to explain why you're saying no. I understand the messaging and agree that we shouldn't have to justify why we can't or don't want to do something, but in practicality, this doesn't work so well. Imagine the awkward silence that would come if someone asks you to grab some dinner or drinks with them after work, and you respond with only a no. Just the thought of doing that makes me anxious. If you're still learning how to say no, I'm right there with you. Let's explore this topic together.

Friends and family. Our 20s are one of the most social times of our lives. It's normal to want to go out with friends just as much as wanting to stay in under the covers and binge-watch a favorite TV show. But sometimes, friends and family can have unrealistic expectations of one another, making it difficult to say no or set boundaries. Setting boundaries becomes especially difficult if you have friends or family members who don't understand your illness or the challenges you face. No matter how many times or ways we try to help people understand what we go through, some people just don't get it. Something that helps me is reminding myself that they are people, too, with their own set of unique beliefs and values. Even if we are family or best friends, it doesn't mean we act and think the same.

Work and school. Saying no to school or work requests is challenging, especially at the start of one's career. It's essential to be the best person you can be, whether a student or worker, but not at the expense of your health or well-being. The reality is we are replaceable at our jobs. If we weren't there, they would hire someone else. We are not replaceable in our families or our friend groups. When we get sick from stress or from being overworked, we are the ones who suffer. Before starting a new job, it's helpful to ask what the responsibilities and work hours will be and what paid time off, sick time and benefits are offered. How an employer responds to these questions can tell a lot about the workplace environment and culture. Individually, it would be best to evaluate what you need from a job, such as health insurance, enough sick days, etc., and your boundaries, such as not working on weekends or not working during your lunch break. It's a lot easier to start a job with your boundaries known and in place rather than trying to implement them after months or years of working somewhere. If you consistently work during your breaks, for example, people will start to expect that from you.

Giving reasons and justifications. I give a lot of credit to those with firm boundaries who say no to things they can't or don't want to do without overexplaining or justifying their decision. I've been learning that sometimes less is more with what you say. Honestly, no matter what you do or don't say, there will always be people who take it the wrong way, make assumptions or get upset. The best we can do is be genuine and kind and make decisions based on what is best for us, especially when we have chronic illnesses to worry about and control. Not everyone will understand, so sometimes it's better not to explain. If someone genuinely asks for an explanation, that would be a good time to talk about the reasons for your decision if you feel comfortable doing so.

Realistic expectations. At the end of the day, you only have yourself. You will be left with your feelings and emotions when you go to bed every night and wake up each morning. Nobody understands what goes on inside of you but you, and that's who you must stay true to. Also, when possible, it's easier to reflect on our boundaries and wants before we're put on the spot to make those decisions. We must have realistic expectations and remember that only some people will understand or agree with our choices. The goal isn't to have people agree with you. I think the goal is to feel comfortable with ourselves and our choices. You got this! 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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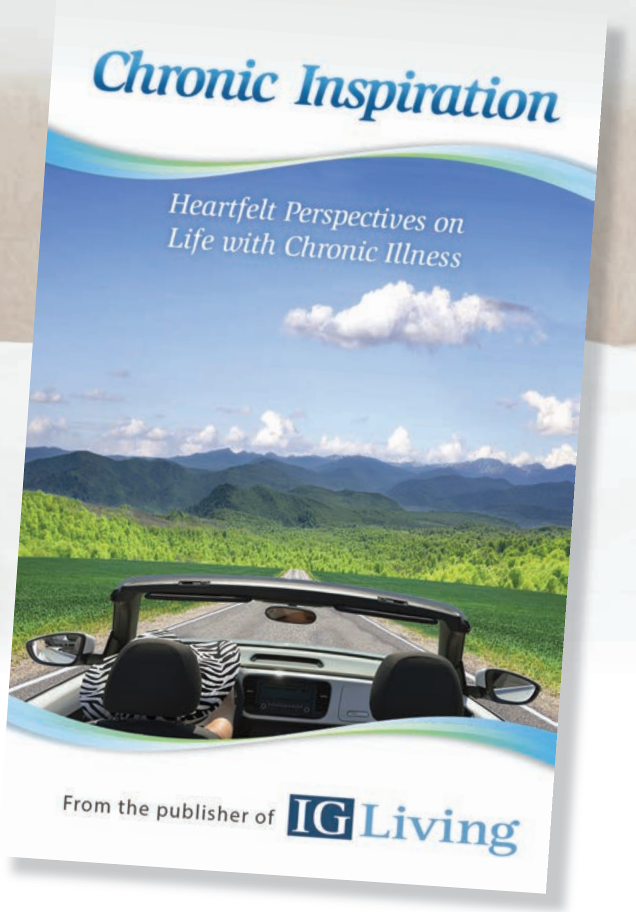


"You can lament what is lost to you, whether it's opportunity, a person or your health, but clinging to anger is no way to experience life." — Rebecca Zook in "Life Lessons," excerpted from *Chronic Inspiration.*

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

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

— Jenny Gardner

IG Living

Chronic Inspiration can be purchased on iTunes, Amazon and Barnes and Noble.com

Let’s Go to Work!

By Whitney L. Ward

GUESS WHAT? I started my first full-time job! I’m now a third grade teacher, and I love it. My students are the absolute best.

But, you might be wondering how can I have a full-time job and still qualify for Medicaid benefits. That’s why this patient perspective column is so exciting for me to write. After five years of getting no answers, the doors finally opened in 2019 for me to begin meeting with U.S. congressmen and senators. In the June-July 2021 issue of *IG Living*, I wrote an article titled “Balancing Government Assistance and Career Goals,” which detailed what I discovered from these meetings.

I recently had the honor of meeting with Ohio Rep. Brad Wenstrup one last time before he retires from Congress. And that gave me the idea to provide some insight about programs for chronically ill patients who want to work, but who fear losing their medical insurance, which they need for their lifesaving, costly treatments that enable them to work in the first place. So, this perspective is a full circle moment for me.

To start, there is a difference between federal and state programs. All Americans are entitled to federal programs regardless of where they reside. State programs apply only to the people living in that particular state.

Unfortunately, most people with chronic illnesses either aren’t unaware of or have been given misinformation about a federal program that provides a path to the workforce. Chronically ill patients qualify for the 1619b plan even when receiving Medicaid. To qualify, patients must:

- Be eligible for Social Security Income (SSI) payments for one month;
- Still meet the disability requirements;
- Meet all other non-SSI requirements;
- Need Medicaid benefits to continue to work; and
- Have gross income earnings that are insufficient to replace SSI, Medicaid and other publicly funded attendant care services.


Whitney Ward with Rep. Brad Wenstrup

The 1619b plan uses a threshold to determine what the insufficient gross income earnings need to be to remain on the plan. This cap is determined by each state’s cost of living. To find out what your state’s threshold is, visit www.ssa.gov/disabilityresearch/wi/1619b.htm.

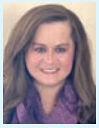
State programs come into play when and if you exceed the federal 1619b threshold. Unfortunately, some states are better about taking care of their residents than other states. I live in Ohio, so I’ll share what my state offers its constituents with disabilities through my county’s Job and Family Services office. As an Ohioan with a disability, I’m eligible for the Ohio Medicaid Buy-In for Workers with Disabilities (MBIWD). An Ohioan qualifies for this if they meet the following criteria. They must:

- Be between 16 and 64 years of age;
- Be disabled as per the Social Security Administration or as determined by Ohio Medicaid, or eligible under the MBIWD medically improved category;
- Be employed in paid work (including part-time and/or full-time work);
- Pay a premium (if applicable);
- Meet certain financial requirements, including a monthly income less than or equal to 250 percent of the federal poverty level); and
- Comply with annual MBIWD resource eligibility limits.

Each state differs in what it offer its residents, so it’s crucial before going beyond the federal 1619b plan to research what your state offers to persons with a disability who want to be employed.

I hope this encourages you to know there is a path to employment. Be tenacious, seek answers and demand that you be given the assistance you deserve. We were created to do so much *more* than just exist. So, let’s get out there, let’s show the world our perseverance and, above all, let’s get to work!

More information about this topic can be located at medicaid.ohio gov/families-and-individuals/citizen-programs-and-initiatives/medicaid-buy-in-for-workers-with-disabilities and www.ssa.gov/disabilityresearch/wi/1619b.htm.



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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Wearables for Kids: Helpful or Harmful?

By Jessica Leigh Johnson

WEARABLE TECHNOLOGY, now often referred to as "wearables," is any kind of device that people can wear on their bodies. Wearable health-tracking and medical devices are nothing new. Patients have been "wearing" pacemakers since the 1960s and hearing aids since the 1980s.[1] Heart monitors, glucose meters and skin patches have been around for decades. But with today's ever-evolving technology and the prevalence of smartwatches and fitness trackers, wearables have hit a whole new level of popularity and have a wide range of applications, especially for those who suffer from chronic health conditions.

Today, wearables are increasing in popularity among children and teens, but unfortunately, most of these technologies were developed with adults in mind. The question is, are there any wearables that are safe and beneficial for kids? And what precautions do parents need to take if their children use them?

What Are the Benefits of Wearable Health and Fitness Devices?

Wearables use built-in sensors to collect data about the users' health and have many potential health benefits. Activity trackers such as Fitbits use these sensors to capture real-time data on individuals' movements, including step count and levels of physical activity, as well as biometric data such as heart rate. Using the collected data, these devices provide feedback through apps that can be installed on smartphones or other devices, allowing users to track their fitness and monitor their health conditions.[2]

Some programs allow the data that is collected from certain devices to be shared with doctors and other healthcare professionals who can use the information to make decisions regarding healthcare without patients ever stepping foot in the clinic. Because of these applications, wearables are beginning to play an important role in the detection, prevention and control of chronic conditions by providing important health information in far less time than it would take a doctor or nurse to discover that same information from a physical exam.[2]

Of particular benefit to kids is that most of these wearable devices encourage them to be active, and getting in the habit of moving around and being active will bring about a multitude of health benefits. Of course, not every device is going to work for every child. Some kids may not like the feeling of something being on their wrists.[2] Others may be distracted by a smartwatch or fitness tracker. Instead of a tool that encourages them to be more active, it becomes just one more device with a screen to look at or play on. Parents have to make the decision about whether or not wearable technology is right for their children.

What Threats Do Wearables Pose?

The purpose of most wearable technology is to collect health data such as weight, movement trends, heart rate, glucose levels, etc. So it should come as no surprise that personal information is being shared with someone on the other side. The problem arises when other personal information such as email, birth date, address and sensitive data that could pose a privacy risk is shared.[1] Before parents install a health-tracking app or set their kids up with any particular

kind of wearable technology, they should first investigate what, if any, information is shared and determine if they are comfortable with that, especially if the information belongs to their children.

Another threat to children using wearable technology designed for adults is the negative impact it could have on self-esteem and body image. Since most fitness and health tracking devices are set up with goals for adults, such as a healthy weight, BMI, heart rate and number of steps per day, the expectations may not be appropriate for children whose bodies are much smaller. This is why it's important for parents to help explain what the numbers actually mean. If children or adolescents misinterpret the data and fixate on it, it could cause feelings of failure or dissatisfaction with goals not being met.[1]

For example, if a child obsesses over needing to get in 10,000 steps per day and can never accomplish this goal, it could lead to negative body image or a dissatisfaction with his or her abilities or fitness level. If a child wants a fitness tracker or smartwatch, he or she should discuss their reasons with a parent, and together they can decide on the purpose of the wearable and how they plan to use it.[1]

One more thing to look out for is whether or not the apps on a particular smartwatch or activity tracker connect the user to strangers. This isn't a huge concern for adults, but if children are using these devices, this could pose some problems. There are some smartwatch apps that allow users to connect to their friends' devices so they can set fitness challenges between each other and create shared goals. For parents who are concerned that their children could be communicating with someone they don't know through their wearable device, it's best to check what apps are installed and whether the apps connect the user to "communities" of other users. In some cases, parents might need to update the privacy settings on the device or within the app to limit interactions with others.[1]

> ***All it takes is a simple online search, and parents should be able to find dozens of fitness trackers or smartwatches that have been designed specifically for kids to use.***

What to Look for When Buying Wearables for Kids

All it takes is a simple online search, and parents should be able to find dozens of fitness trackers or smartwatches that have been designed specifically for kids to use. Some of the features that make certain products more appealing to parents are:[3]

- Parent-managed contacts
- No open app store
- Durability and waterproofing
- Low price (either up front or monthly)
- Closed network (providing Internet access only to specific websites or those pre-approved by parents)
- The ability to put the device in "school mode"
- Location features/GPS tracking
- Kid-friendly features such as youthful icons and colorful backgrounds
- Long battery life
- No camera

Made for Adults, Not Children

Remember that many wearable devices are designed for adults, not children. If children want to use wearable technology, their parents need to make sure they look into what data the device collects and how it might connect children to others. When shopping for wearable technology, try to get a device that is made specifically for kids.

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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.

Combatting the Common Cold

By Rachel Maier, MS

EVERY WINTER, my family comes down with a good old fashioned cold, and when it happens, I do what mothers have done for generations: I make a big pot of ginger-infused chicken noodle soup, swirl cups of chamomile tea with honey and lemon, and remind everyone to slow down and rest.

I also inevitably run to the local pharmacy for tissues, cough medicine and pain relievers because, somehow, we always run out. When I go, I am always bombarded by shelves full of colorful medicine bottles claiming to have cracked the code for "fast action" and "instant relief" that "shortens colds!" (or whatever happens to be the catchy promise du jour). Even supplements such as vitamin C and zinc get in on the hype and flaunt their cold-busting properties. But I have to remind myself: While both over-the-counter medicines and supplements may provide relief from the symptoms associated with a cold, they don't provide a cure, and like it or not, colds last for seven to 10 days. The best any of us can do to combat them is provide comfort and immune support while colds run their course.

A New Spin on the Same Ingredients

How to best do that is a point of contention: Are supplements best, or is cold medicine key? What about homeopathic, natural remedies? There are pros and cons for each, and it seems to come down to how you prefer to deal with being sick.

For those who prefer taking medicine, it may be helpful to remember that while there are a lot of options to choose from, the products all contain some combination of the same ingredients:

Analgesics: Acetaminophen and non-steroidal anti-inflammatory drugs (aspirin, ibuprofen and naproxen sodium) provide pain relief.

Decongestants: Pseudoephedrine and phenylephrine provide short-term relief of nasal congestion.

Expectorants: Guaifenesin relieves chest congestion.

Antihistamines: Chlorpheniramine maleate, diphenhydramine and doxylamine succinate help relieve runny nose, sneezing and watery eyes.

Cough suppressants: Dextromethorphan helps control coughing by blocking the coughing reflex.

At the end of the day, which "new and improved" formula you choose is less important than only taking what you really need. (In other words, if you have a sore throat and nasal congestion without a cough, stick to analgesics and pseudoephedrine and avoid multi-symptom medicines.)

Supplements such as echinacea, vitamin C and zinc contain properties that support the immune system that some swear help kick their colds to the curb. These supplements have been used for generations, too. However, studies are inconclusive as to how much they actually help. If you want to try them, use them in moderation and according to package directions.

Tried-and-True Symptom Relievers

There's a reason people have relied on home remedies for generations, and it's a good one: They help ease the symptoms and make colds a little more bearable. Honey soothes sore throats; tea and soup keep bodies hydrated; lemon contains vitamin C, which boosts the immune system; ginger eases congestion; chamomile brings comfort to ailing bodies naturally; and saline rinses remove mucus from nasal passages. Plus, many of these common items have anti-inflammatory and antimicrobial properties, and they don't contain chemicals or additives the body doesn't need. When my family is sick, we turn to these most often.

Oh, I still like a good cough drop and over-the-counter medicines that actually work. Western medicine harnessed the power of harder-to-find compounds that alleviate symptoms of the common cold, and I'm grateful for them! But again, they help relieve, not remove, the symptoms. Combatting the common cold comes down to hydration, immune system support and rest. Here are six products that help you do just that. IG

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

Vaporeze Menthol + Eucalyptus Vapor Pads for Humidifiers

The jury's still out on whether humidifiers really help relieve symptoms of the common cold, but my kids sure say they do! Humidifiers put moisture back in the air, which helps them breathe a little easier when their noses are super stuffy and sore. Try menthol and eucalyptus-infused vapor pads with your favorite cool mist humidifier. *$19.99; www.amazon.com/stores/Vaporeze/page/CB4F5171-784E-452E-8C0A-7BFC82D0F618*

Baraka Ceramic Neti Pot

The Neti pot is an ancient method of clearing the sinuses. But why settle for using a plastic pot when you can get a beautiful, high-fired ceramic piece that was handcrafted in the United States? The Baraka ceramic neti pot is a durable yet lightweight piece of stoneware finished with food-grade ceramic glaze. It is 100 percent lead-free, safe and nontoxic and, best of all, easy to use. *$28.00; store.sinussupport.com/baraka-ceramic-neti-pot*

Shopping Guide for Combatting the Common Cold

Genexa Cough and Chest Congestion

When the urge to cough just won't quit, cough syrup can be a miracle of modern medicine — especially when you're trying to sleep! But most mainstream cough syrups are made with artificial colors and sweeteners and are loaded with chemicals. If you want reliable cough relief without all the extras, try Genexa's maximum strength cough suppressant and expectorant. It helps temporarily control the urge to cough, relieves chest congestion and thins and loosens mucus. Also try Genexa Kids' Cough and Chest Congestion. *$17.99; www.amazon.com/dp/B0BJHDZ149*

Maty's Vapor Rub

Made with eucalyptus, peppermint and tea tree essential oils, Maty's All Natural Vapor Rub is a great alternative to the petroleum-based national brand we grew up slathering on our chests. Maty's naturally provides soothing relief from congestion without synthetic camphor, petroleum, parabens, hydrogenated oils, artificial fragrances or gluten and is suitable for ages 2 and up.
$14.99; matyshealthyproducts.com/products/vapor-rub

Proper Good Chicken Noodle Soup

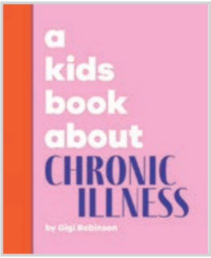
Chicken noodle soup with a swirl of immune-boosting ginger and turmeric without the mess of making it myself? Yes please. This shelf-stable soup is reminiscent of the homemade soup you love, but it's ready in 90 seconds. *Starts at $5.19; eatpropergood.com/products/chicken-noodle-soup*

Traditional Medicinals Get Well Soon Care Package

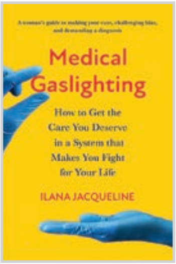
Be ready to take good care of yourself and your loved ones with a stash of Traditional Medicinals' most-loved teas and lozenges. This bundle includes the customer favorite Throat Coat, along with Immune Zoom, Echinacea Plus and Cold Care P.M. teas plus two packs of Throat Coat lozenges. *$47.95; www.traditionalmedicinals.com/products/get-well-soon-care-package*

A Kids Book About Chronic Illness

Author: Gigi Robinson
Publisher: DK Children



Chronic illnesses are lifelong health issues that can make the simple act of growing up feel different for kids who have them. And that can sometimes be lonely and frustrating. But in this book, the author, who also has a chronic illness herself, teaches kids how to reshape their mindset, find new passions and pour their energy into things that empower them and fill their life with joy.

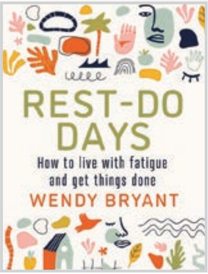


Medical Gaslighting: How to Get the Care You Deserve in a System that Makes You Fight for Your Life

Author: Ilana Jacqueline
Publisher: BenBella Books

For women, the possibility of experiencing medical gaslighting — having a healthcare provider dismiss or ignore their concerns without considering appropriate testing or creating a treatment plan — has always been a real and present danger, with consequences ranging from self-doubt and emotional stress to delayed diagnosis and death. This book, written by patient advocate (and rare disease patient) Ilana Jacqueline, will equip readers with the tools needed to be fully heard at every step of the process, including mastering the ability to request, revise and read their electronic medical records so they and their medical team are on the same page; responding effectively when they recognize the signs, language and scenarios associated with medical gaslighting; and giving them a fighting chance against common medical bias by being mindful of how they present themselves as a patient. Included are expert advice and stories from women across the medical spectrum who fought medical gaslighting and lived to tell their stories.

New and Useful Reading



Rest-Do Days: How to Live with Fatigue and Get Things Done

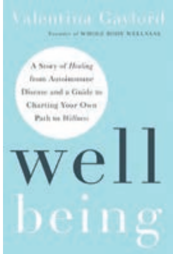
Author: Wendy Bryant
Publisher: Hammersmith Books Limited

This is a practical guide to finding a balance between resting and doing so readers can recharge their energy levels and also do the things important to them. Using concepts from occupational therapy about pacing, occupational balance and creativity in everyday life, this approach is based on the author's professional experience as an occupational therapist and her personal experience of living with chronic illness through which she has learned how to adapt her rest-activity balance, keeping an eye on what (or who) is controlling her decisions and focusing on doing what's important and satisfying in her life. The book is aimed particularly at sufferers from degenerative diseases that involve high levels of cyclical fatigue with no expectation of cure.

Well Being: A Story of Healing from Autoimmune Disease and a Guide to Charting Your Own Path to Wellness

Author: Valentina Gaylord
Publisher: Hay House LLC

In *Well Being*, Valentina Gaylord dissects the course of her own decline from exuberant wife, mother and fitness entrepreneur to pain-riddled, exhausted and desperate victim of disease. Drawing on her personal experience and intensive research, as well as her work with clients in the boutique fitness studios she founded and owned for more than 10 years, Gaylord shares exercises and techniques that put mindset, emotional wellness and spiritual awareness at the forefront of health. In each chapter, she offers thoughtful questions and carefully crafted journal prompts.



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* Produced by IG Living magazine, written for patients treated with immune globulin therapy and their caregivers.

Abbie Cornett, MBA
IG Living Patient Advocate

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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Every quarter, IG Living will hold a podcast on a topic that affects those with autoimmune and immunodeficiency disorders. Industry experts will share the latest immune globulin (IG) news and information and answer questions from our community.

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