IGLiving

August-September 2025

IGLiving.com

Effective Communication

Building Better Habits

Managing Fatigue Using Pacing Activities

How Fitness Can Improve Daily Functioning

Maintaining Gut Health While on Medication

Diagnosing and Treating IPEX Syndrome

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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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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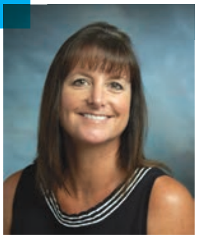
From the Editor

Three Ways to Make Life More Manageable



THREE IMPORTANT tools work best when used together: effectively communicating, learning how to manage fatigue and incorporating fitness into your life. When combined, they can make daily life with a chronic illness a little easier and more manageable.

Effective communication is crucial, especially when dealing with health issues. We provide simple tips for communicating more purposefully in our article "Your Voice Matters: Practical Tips for Intentional Communication" (p.24). This includes speaking intentionally by thinking about word choices, and being aware of what you are saying and how it relates to your thoughts and feelings — skills that are essential to patient-physician communication. The practice techniques suggested in this article will improve your communication during doctor visits. And, importantly, learning good listening skills will make your doctor conversations more meaningful. Try using the practice exercises to make better communication a habit.

Fatigue, one of the most common concerns of patients with chronic illness, requires learning how to pace your activities on a daily basis. Fatigue coach Pamela Rose provides insight into how to manage your daily energy levels through creating your own energy sizing scale in our article "Pacing Your Activities for a Balanced Life" (p.32). She explains that your energy management plan will be unique to you; it will require giving more detailed thought to your days' activities by prioritizing daily tasks in advance and identifying how much energy you can commit to those tasks. And, while you may find incorporating an energy management plan difficult because it will require more energy at first, Pamela merely asks "Why not try doing things differently just for a couple of weeks?" to see the difference it will make.

Speaking of energy, it's common for many with chronic illness to feel that exercise is not only impossible, but that it may not be good for you since one of the most prevalent fitness myths is that exercise weakens the immune system. But, as we explain in our article "How Fitness Can Improve Daily Functioning" (p.36), recent studies have found just the opposite: Exercise actually *benefits* people with compromised immune systems. Understandably, most people with chronic illness will find exercise difficult, but it's important to remember that it's not a competition. You have to take your own approach to exercise based on your condition. It's not about "pushing through the pain," but listening to your body. Try some of the suggested fitness activities that can make you "stronger, more limber and better able to perform everyday tasks."

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
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When Treatment Fatigue Takes Over

By Abbie Cornett, MBA

HAVE YOU ever woken up and felt the weight of the day before you even opened your eyes? The first thing on your mind isn't breakfast or plans, it's your illness. You think about how much has changed: the pills you take every day, the never-ending tests, the side effects and how every part of your life now revolves around appointments and treatments. You're already tired, and the day hasn't even started.

That's what treatment fatigue feels like. It's a kind of tired that goes beyond being sleepy. It weighs on your mind. It follows you everywhere. Treatment fatigue happens when you're worn out from the effort it takes to manage a long-term illness. People with conditions such as immune deficiencies, autoimmune diseases or other chronic illnesses often feel it.[1] It builds over time. You keep showing up, doing what needs to be done, but deep down you're running on empty.

You may be feeling treatment fatigue if:[2]

- You dread going to the doctor
- You're tired of talking about your health
- You feel frustrated, angry or numb
- You catch yourself wanting to skip meds or cancel appointments
- You're doing everything "right," but still feel worn down

It's easy to feel guilty about this, but let's be clear: Treatment fatigue doesn't mean you're weak. It means you've been strong for a long time, and you're tired. So, what can help?

Talk to your doctor. Your medical team can't help if they don't know how you're feeling. If you're burned out, say so. If something isn't working, speak up.[3] You don't have to suffer in silence. There may be ways to ease your treatment schedule, adjust medications or provide more support. Even small changes such as switching infusion times or treating side effects more directly can make a big difference.

Give yourself breaks. Rest is part of treatment, not a reward for finishing it. Build in small pauses throughout your day. Sit quietly, take a slow walk, lie down for 10 minutes — whatever helps you breathe a little easier. If you're working or in school, ask about flexibility.[4] A shorter shift or a longer break can help you keep going without burning out.

Keep things simple. Chronic illness makes life unpredictable. On days when you're running low on energy, stick to the basics. Take your meds. Drink water. Eat something. Do one thing that brings you peace, even if it's just sitting outside or listening to music. You don't need a perfect routine; you need one that works for you.

Say no when you need to. You are allowed to say no. No to extra plans. No to explaining yourself. No to pushing through when your body is asking you to stop. Resting doesn't make you selfish, it makes you smart. Protecting your energy isn't giving up. It's choosing what matters.

Let the hard days be what they are. Some days will be harder than others. That's the truth. It's OK to feel sad. It's OK to feel angry. It's OK to cry. You don't need to be positive all the time. You need to be honest. Some days, getting out of bed is enough. And if that's all you did today, it counts.

You're not doing it wrong. On those mornings when you wake up feeling tired and overwhelmed by your illness and treatments, remember treatment fatigue is part of the journey. You didn't ask for this, and you didn't choose it, but you're still here, doing the best you can. That's what matters! Remind yourself: You've made it through every hard day before this one. You'll make it through this one, too. You don't have to be perfect. You don't have to be strong all the time. You just have to keep going — and take care of yourself along the way.

References

1. Heckman, BW, Mathew, AR, and Carpenter, MJ. Treatment Burden and Treatment Fatigue as Barriers to Health. *Current Opinion in Psychology*, 2015 Oct 1;5:31–36. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC4465180.
2. Taub, J. 5 Ways to Manage Chronic Illness Burnout. CSL, June 4, 2024. Accessed at www.csl.com/we-are-csl/vita-original-stories/2022/5-ways-to-manage-burnout.
3. Rocketto, L. How to Fight Fatigue from Chronic Illness and Preserve Your Energy During the Day. Living with Arthritis, Oct. 19, 2021. Accessed at creakyjoints.org/living-with-arthritis/chronic-illness-increase-energy.
4. Andersen, CH. 20 Strategies for Fighting Fatigue from Chronic Illness. Living with Arthritis, June 17, 2019. Accessed at creakyjoints.org/living-with-arthritis/chronic-illness-fatigue-tips.

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What's the Most Ridiculous Comment You've Heard?

When I mentioned that I have an autoimmune disease, a friend told me that I should take some sort of supplement, and it would "supercharge my immune system." I told him that my immune system is already overactive, and that is my problem. He looked at me like I was nuts. In any case, those supplements are basically a scam.

A doctor early on told me that when patients get really sick from IVIG, it means "they got the good stuff." Another from a family member while looking for a parking spot and telling her I had my handicapped tag, [she] told me we should save that for people who truly are handicapped. I have multifocal motor neuropathy, a progressive, neurological disease.

Had an ER doc ask me: "So with your immune deficiency, how long do you typically stay sick?" Me: Last upper respiratory infection was four months. Him: Four months!!! [He] left the room mumbling to himself. I was then admitted for croup and sepsis.

Oh, you still have that?

The ones from medical professionals are the most ridiculous to me because, of all people, they should know better. An anesthesiologist once told me my immune deficiency could be cured with Tagamet. Also, a resident wrote down I had "IVIG deficiency," which isn't even a condition, instead of common variable immune deficiency.

If you are overweight, the doc will say lose weight and you won't be sick. But the skinny patients get all the tests. You have to come back to the ER three times, and then they find out you have pneumonia.

From an MD: "It's just your depression." "You seem to be trying to find something wrong; have you considered therapy?"

I Wish My Doctor Knew ______ About Living with a Chronic Illness.

How it affects every aspect of your life. I have multifocal motor neuropathy and primary immunodeficiency, and it affects my daily living from the second I wake up until I go to sleep.

I'd like to be believed.

That we aren't making up our symptoms. [It] doesn't matter if it's one or 100, rare or common. If we tell you about it, then it's happening and happening often enough that we need to tell you about it.

We are not lazy and "moody."

That it can't just be brushed aside. I tell specialists about it, but they don't care, when I feel it plays a huge part in my treatment plans.

How utterly and completely time-consuming and mentally and physically draining managing our illness is. Between treatments, tests, doctor appointments, managing meds, picking up meds and, on top of it all, being sick constantly.

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.

When Infusing IVIG, I Am Treated with Steroids That Cause Sleeplessness. What Can I Do to Help Me Sleep?

I have been receiving monthly intravenous immune globulin (IVIG) infusions for common variable immune deficiency (CVID) for the past 10 years with great results. My doctor gives me steroids with the infusions, which keeps me up almost all night on treatment day. We tried the treatment without the steroids, and the results weren't good. I had a reaction that I don't want to go through again. What can I take to help me sleep? I've tried Benadryl, Xanax and, most recently, Ambien. Nothing works. Can you recommend anything else?

Abbie: I'm glad to hear you've been doing well on monthly IVIG infusions for your CVID. It's not uncommon for people to experience side effects from IVIG infusions, and I completely understand how difficult it must be to have trouble sleeping following treatment, especially when steroids are part of your premedication routine.

While I'm not a medical provider and can't recommend specific medications or supplements, I would strongly encourage you to speak with your prescribing physician about other possible options. Since you've already tried Benadryl, Xanax and Ambien without relief, it may be helpful to reevaluate your treatment protocol with your doctor.

In some cases, patients have had success switching to a different brand of IVIG, which might be better tolerated and may not require steroids. Others have transitioned to subcutaneous IG therapy, which often allows for fewer side effects and more flexibility. Of course, any changes should be made in close coordination with your healthcare provider.

In the meantime, consider incorporating nonmedication-based strategies for improving sleep. Many people find gentle practices such as mindfulness meditation, breathing exercises or progressive muscle relaxation before bed can help calm the mind and body. Some helpful apps and websites include:

- Calm (www.calm.com): offers guided meditations, sleep stories and relaxing music
- Insight Timer (www.insighttimer.com): provides free access to thousands of meditations and sleep tools
- Headspace (www.headspace.com): offers structured meditation programs, including ones focused on sleep

You may also find it useful to limit screen time in the hour before bed, reduce caffeine later in the day and keep your sleeping space cool and quiet. Small changes such as these can sometimes make a noticeable difference.

Again, I would recommend discussing all of this with your doctor to come up with a plan that keeps you both comfortable and safe.

Is It Safe for Patients with Low IgA Levels to Be Treated with SCIG?

I just finished reading the April-May issue of *IG Living* magazine, and there was a question about subcutaneous immune globulin (SCIG) and low immunoglobulin A (IgA) levels. Your response to this patient was that SCIG is safe for low IgA levels. However, if you have low IgA levels, you cannot be prescribed all brands of SCIG. I very rarely have low IgA levels, but the one time I did and took my monthly dose of SCIG, I ended up in the ER with a very nasty allergic reaction to it. You may want to research this and get back to that patient!

Abbie: I spoke with Roger Kobayashi, MD, an allergist-immunologist in Omaha, Neb., who shared that while SCIG is generally safe for most patients with low IgA levels, caution is still advised in rare cases, especially for individuals who have developed anti-IgA antibodies. It's always best to work closely with an experienced immunologist to ensure the safest and most effective treatment. We truly appreciate you sharing your experience. It helps us better support the community!

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

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Do I Need Therapy? Understanding the Landscape of Mental Health Services

By Mairead McConnell, PhD

IN RECENT years, therapy has grown in popularity as mental health has become more openly discussed and destigmatized. Perhaps you have seen therapy services advertised in commercials or hear friends talking about their therapist. The good news is that therapy is no longer shrouded in shame — but it is still enough of a mystery that many people often wonder: "Do I need therapy?" and if so, "Where do I even begin?"

For those living with illness or immune conditions, navigating the world of healthcare is already challenging. It may feel daunting to search for a mental health provider who also understands your condition and can offer the right support. The good news is that good mental healthcare is out there, and knowing what to look for can help you connect with the right resources.

If you are: overwhelmed by navigating issues related to your health, dealing with health-related anxiety, struggling to adjust to your condition or make lifestyle changes.

Consider seeing a: clinical health psychologist (PhD or PsyD). Clinical psychologists are trained in evidence-based interventions to treat mental health conditions. They specialize in working with people whose medical illness impacts their mental health and vice versa, and they can help you learn tools to cope and move forward in effective ways.

If you are: interested in medication to treat your mental health condition.

Consider seeing a: psychiatrist (MD, DO) or psychiatric nurse practitioner (PNP). Psychiatrists are able to evaluate and prescribe medications for a number of mental health conditions. Medication is not always necessary or right for everyone, but it is one of the treatment options available. Research shows a combination of both medication and therapy is the most effective way to manage many conditions.

If you are: wanting to change patterns of thinking, improve relationships and focus on personal growth.

Consider seeing a: therapist or counselor. Individual therapy can be provided by a psychologist (PhD/PsyD), licensed clinical social worker (LCSW), licensed professional counselor (LPC) or licensed mental health counselor (LMHC). Finding the right provider is about finding someone who feels like a good match for your needs. Know that therapy isn't only for those who are suffering with mental illness. If you feel like things could be better and are ready for personal growth, there are therapists who focus on positive psychology, growth and thriving.

Where to find them: Ask your primary care physician or trusted medical provider if he or she has a recommendation, or contact your insurance for a list of covered providers. Another excellent resource is psychologytoday.com, which has a therapist finder tool to search for a psychologist, psychiatrist, counselor or even a support group. You can filter by specialty and even the type of insurance you have.

If you are: struggling to feel understood in your experience and wishing to talk to others going through similar circumstances.

Consider: attending a support group. Support groups provide a community of individuals who are going through something similar, helping you feel less alone. Some organizations have in-person groups, and many have online support groups and forums.

Where to find one: Search online for a group that applies to you. Some groups are for specific conditions while others are for anyone with chronic illness. Keep an open mind; before you dismiss it, check it out and see what it's about.

If you are: feeling hopeless, thinking life may not be worth living or thinking about harming yourself.

Please know: you are not alone. Help is available; things can get better. Call the National Suicide Hotline: 9-8-8. It can help connect you to your local emergency services, or you can seek help in the emergency department. If you are not in an emergency situation but need someone to talk to, consider calling a Warm Line (www.warmline.org), which offers non-crisis emotional support and resources to those experiencing stressful situations, anxiety or challenges.

Your mental health is one of the most important things you can invest in. While therapy can be expensive, almost every insurance provider covers some behavioral health services. IG

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

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

- **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

*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.

panzyga®

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

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

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

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?

PANZYGA is a liquid medicine for infusion that contains immunoglobulin G (IgG), which are proteins that help fight infection. PANZYGA is used to treat 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 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).

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.**

Who should NOT use PANZYGA?

Tell your healthcare provider 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

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
- 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 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

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. If you encounter any problems or experience side effects during or after the infusion, contact your healthcare provider. When doing so, keep your therapy tracker with you to be able to give all necessary information.

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

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

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

PANZYGA® is a registered trademark of Octapharma AG.

Pfizer | octapharma®

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

SARS-CoV-2 and COVID-19: Brain Fog Evaluation and Treatment

By Terry O. Harville, MD, PhD

IN THE last issue, we discussed the processes contributing to brain fog in patients with long COVID. One of the major causes appears to be due to persistent activation of microglial cells in the brain, along with the production and secretion of inflammatory cytokines and chemokines, which disrupt normal neuronal function. The microglial cells have been converted to the inflammatory M1 state due to the COVID infection and have been unable to revert to the anti-inflammatory M2 state. Another cause may be due to microclotting, which likely occurs due to autoimmune antibodies generated because of COVID, including the anti-ACE2 antibody we discovered. These autoimmune antibodies bind to the endothelial cells of the blood vessels, activate complement and result in damage, which in turn activates clotting. The reduced blood flow contributes to brain dysfunction and brain fog. Both of these processes can occur in the same person.

To diagnose brain fog, our clinical evaluation includes questions asked of patients with long COVID that elicit responses such as: "I get lost in the middle of answering a question," "I cannot think of the correct word," "I forgot what I was doing," "My thinking is slow," "I sometimes do not understand what someone is trying to tell me," "This prevents me from being able to work," etc. It is not uncommon for patients to also experience headaches that had not previously been present. Patients may have new-onset tinnitus (ringing in the ears). And, patients commonly report occasional visual disturbances such as the visual images are out-of-sync with what is occurring, or occasional pixelation of vision. All of this is disturbing to patients with long COVID, and frequently, it is their major reason they are seeking treatment.

Thus, a diagnosis of brain fog can be made based on clinical features and symptoms. The laboratory evaluation includes testing for items suggested by the interview and physical examination. In particular, we test for D-dimers and fibrinogen levels, elevations of which suggest a patient is experiencing clotting in his or her blood vessels.

We stress that vaccination can prevent long COVID if patients are immunized before the infection, and importantly, continued revaccination can reduce symptoms of long COVID. We suggest being vaccinated with the Pfizer vaccine based on its properties and receiving vaccinations every six months, as possible. Otherwise, our treatment is focused on reducing brain inflammation, which requires therapies that can convert the M1 microglia to the M2 state and disrupt the inflammatory cytokine and chemokine production. Based on the literature and our personal experiences, we have found the following to be very effective: 1) 4.5 mg (low-dose) of naltrexone each evening (beginning with 1.5 mg each evening for a week, then 3.0 mg each evening for a week, then 4.5 mg; occasionally we increase to 6 mg and, possibly, to 9 mg); 2) 15 mg of melatonin taken at sundown; 3) 600 mg of N-acetyl-cysteine three times a day (or 1,000 mg twice a day); 4) 2,000U of vitamin D3 twice a day; and 5) 100 mg or 200 mg of celecoxib twice a day (based on patient size). If excessive fatigue is also present that prevents good concentration, we may add Adderall or Dexedrine as blood pressure issues allow. Since most patients also have POTS (postural orthostatic tachycardia syndrome), these stimulants serve two purposes. We have prescribed modafinil in those who continue to have excessive tiredness/sleepiness despite direct stimulant therapy.

If D-dimers and fibrinogen levels are increased, which is a sign of clotting, we begin 5 mg of apixaban twice a day. Once begun, we continue this long-term until all features of long COVID are fully resolved. We hope this will help prevent dementia.

Our treatment approach is working for nearly all of our patients. However, we do further individualization as needed for those not fully improving.

In the next issue, we will further discuss evaluation and treatment of brain fog. IG

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

Adrenal Fatigue: A Controversial Diagnosis

By Michelle Greer, RN, IgCN

ADRENAL FATIGUE is a buzzword in the alternative health community used to describe a group of vague symptoms a person may experience when the adrenal glands can't keep up with the demands of chronic stress. Symptoms usually include tiredness, weakness, sleep problems and salt and sugar cravings. But is adrenal fatigue a real thing?

Understanding Adrenal Glands

The adrenal glands perform several functions, most notably producing various hormones to help regulate metabolism, the immune system, blood pressure and stress response. There are two adrenal glands: Each one is located on top of one of the kidneys. They are small, specialized organs comprised of the cortex on the outside and the medulla on the inside.

- *Adrenal cortex.* The adrenal cortex is made up of zones, and each zone produces a specific steroid hormone:

  - Glucocorticoids. Glucocorticoids are cholesterol-derived steroid hormones. They are anti-inflammatory in all tissues, and they control metabolism in muscle, fat, liver and bone. They also affect vascular tone. In the brain, they influence mood, behavior and sleep-wake cycles. Cortisol is a glucocorticoid.

  - Aldosterone. Aldosterone is the major circulating mineralocorticoid, a steroid hormone that primarily maintains electrolyte equilibrium, which contributes to the stabilization of blood volume and blood pressure.

  - Androgens. Androgens are sex hormones. Although males naturally produce more androgens than females, androgens are found in both sexes and keep the body on track with sexual development and overall health. Androgen levels can change throughout the day, and different life stages such as puberty or menopause affect hormone levels as well. In males, androgens contribute to a deepening voice, hair growth and sperm development; in females, they contribute to breast development, menstrual regulation and conception. They also help with bone density and muscle development in both sexes. Testosterone is the most common androgen.

- *Adrenal medulla.* The adrenal medulla produces hormones known as catecholamines, which play a major role in stress response. The two main catecholamines are adrenaline, also known as epinephrine, and noradrenaline, also known as norepinephrine. The stress response is also called the fight or flight response, which can occur due to physical or emotional stress. Catecholamines affect involuntary body functions that we don't have to think about, namely heart rate and breathing. Within moments of a perceived stressor, heart rate and breathing may increase, blood pressure might increase, muscles could tense up and sweating and dry mouth can also occur. During a fight or flight response:

  - Adrenaline will deliver additional oxygen to the muscles by dilating airways, increasing blood pressure and widening smaller arteries, which increases cardiac output. Adrenaline can increase strength and heighten awareness. It also impacts pain perception. Adrenaline levels can decrease gradually, so these effects can last even when the stressful experience is over. This is why the onset of pain can be delayed with physical injury sustained during a stressful situation.

  - Noradrenaline is a hormone, but it is also a neurotransmitter. It affects metabolism by increasing blood sugar levels and controls blood pressure in conjunction with constriction of blood vessels. In the brain, it plays a role in sleep cycles, memory, concentration and emotions.

Adrenal Insufficiency

If the adrenal glands do not produce enough of any one of these hormones, it is known as adrenal insufficiency. When adrenal insufficiency happens without a cause, it is known as primary adrenal insufficiency, which is rare. Primary adrenal insufficiency is treated by replacing the deficient hormone(s) with a synthetic version of the hormone. An example of primary adrenal insufficiency is Addison's disease, in which cortisol production is affected. Symptoms are numerous and include extreme fatigue, salt cravings and weight loss. Other disorders of the adrenal glands include those that involve overproduction of hormones and tumors.

Why Is Adrenal Fatigue Controversial?

So, what is adrenal fatigue? It is a diagnosis used by alternative medical practitioners that is not accepted by most physician groups.

The term was coined around 2000 by James L. Wilson, DC, ND, PhD, a chiropractor and naturopath who is no longer in practice. He saw patients with symptoms similar to adrenal insufficiency whose cortisol levels were normal and who did not have Addison's disease. Dr. Wilson used the term "adrenal fatigue" to describe what he described as a mild form of adrenal insufficiency caused by chronic stress; it is thought to occur when the body experiences a prolonged state of stress and the adrenal gland cannot keep up with the demand of hormone production needed for a proper stress response. The resulting symptoms are the opposite of what happens during a fight or flight response: fatigue and weakness instead of strength; brain fog instead of alertness; and poor memory, disrupted sleep-wake cycles, depression and anxiety.

But endocrinologists, physicians who specialize in disorders involving hormones and glands, do not recognize adrenal fatigue as a true medical condition. There is no test for adrenal fatigue, so the diagnosis is based solely on symptoms, which can be indicative of a variety of medical diagnoses.

In January 2022, the Endocrine Society published an article addressing adrenal fatigue and warning of the dangers associated with the diagnosis, saying, "No scientific proof exists to support adrenal fatigue as a true medical condition." Further, the society cautions patients given this diagnosis: "Doctors are concerned that if you are told you have this condition, the real cause of your symptoms may not be found and treated correctly. Also, the reported treatment for adrenal fatigue is not approved by the U.S. Food and Drug Administration (the government agency that oversees most food and medical products) and may be expensive since insurance companies are unlikely to cover the costs."[4]

There is also concern that supplement treatment(s) for adrenal fatigue can cause more damage. The society cautions that if people take adrenal hormone supplements when they are not needed, adrenal glands may stop working and become unable to make the hormones that are needed during times of physical stress. When someone stops taking these supplements, their adrenal glands can remain "asleep" for months. People with this problem may be in danger of developing a life-threatening condition called adrenal crisis.[4]

All this being said, much of the treatment for adrenal fatigue does support a healthy lifestyle and are good habits to form anyway. This includes a proper diet that includes avoiding processed foods, excess sugar, caffeine and alcohol, and being sure to eat healthy fats, fruits, vegetables, fermented foods, herbs and spices such as garlic, turmeric, ginger and cinnamon. Eliminating stress, which seems easier said than done, is key. This is typically defined on an individual basis as to what stress is and how to ease or eliminate it. Activities may include various exercises (walking, yoga, lifting weights), breathwork, meditation, massage and positive self-talk. Establishing and maintaining healthy sleep habits are also important, including a consistent sleep schedule and pattern, avoiding screens before bed and implementing other wind-down rituals. In addition to sufficient nighttime sleep, short naps can be helpful.

Real Symptoms, Reliable Care

Whether or not adrenal fatigue is a true medical condition, the bothersome symptoms associated with it are real. If you experience prolonged stress, persistent fatigue or low energy, difficulty concentrating or cravings for salty or sweet foods, talk to your doctor. A licensed physician will evaluate you to determine the root cause of what is going on by gathering medical history, conducting a physical exam and ordering proper tests. Hormone replacement therapy may be necessary (if the patient is experiencing adrenal insufficiency); supplements are not necessarily the answer; and healthy lifestyle choices are always an integral part of any treatment plan to support adrenal gland function. IG

References

1. Caratti, G, Pfänder, P, and Matthews, L. Glucocorticoids: Restoring Balance During Stress. *The Endocrinologist*, Issue 130, Winter 2018. Accessed at www.endocrinology.org/endocrinologist/130-winter18/features/glucocorticoids-restoring-balance-during-stress.
2. Furman, BL. Mineralocorticoids. In, *Reference Module in Biomedical Sciences*, Elsevier, 2017. Accessed at www.researchgate.net/publication/312114197_Mineralocorticoids.
3. Cleveland Clinic. Androgens. Accessed at my.clevelandclinic.org/health/articles/22002-androgens.
4. Endocrine Society. Adrenal Fatigue, Jan. 25, 2022. Accessed at www.endocrine.org/patient-engagement/endocrine-library/adrenal-fatigue.

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

HONOR

IG Living Advocate Podcast Selected as a Top 100 Web Podcast

FeedSpot, a company that categorizes global media outlets and content creators to make them easy to discover, follow and contact, has selected the IG Living Advocate Podcast as number 22 in the "Top 100 Best Chronic Illness Podcasts" on the web. Individuals can access all episodes of the IG Living Advocate Podcast at podcast.feedspot.com/chronic_illness_podcasts.

Begun in 2019, the podcast has 17 episodes on topics ranging from "The Increased Demand for Immune Globulin Products and Its Effects on Patient Access" to "Changes in Medicare That Affect Patients Treated with Immune Globulin," "The Road to Diagnosis," "Advocacy Versus Self-Advocacy," "How to Stay Positive and Refuse to Let Your Illness Define You," "Living Well with Chronic Illness" and much more. All of the podcasts can also be accessed at the IG Living website at www.igliving.com/life-with-ig/ig-living-advocate-podcast.html.

Readers can suggest topics for the IG Living Advocate Podcast by emailing IG Living's patient advocate and podcast host Abbie Cornett at acornett@igliving.com or by suggesting questions and topics for future podcasts on the IG Living Advocate Podcast site listed above.

CONFERENCE

IDF to Hold Medical Summit for Clinicians

The Immune Deficiency Foundation (IDF) will host a Medical Summit Oct. 8-9, 2025, for clinicians to help them strengthen their clinical toolkit, network with leaders in the field of immunology and connect the dots on primary immunodeficiency (PI) care. This comprehensive two-day event is designed specifically for immunology-adjacent healthcare professionals seeking to enhance their ability to serve patients with PI.

Attendees will earn continuing education unit (CEU) credits while participating in expert-led sessions covering the full spectrum of PI care, including:

- Identifying strategies for recognizing PI patients within diverse clinical presentations
- Advanced diagnostic approaches and testing protocols
- Current treatment modalities and emerging therapies
- Management of common comorbidities
- Practical guidance for navigating insurance challenges and treatment authorization
- Cultural considerations for managing chronic conditions
- Expert strategies for long-term patient support and care coordination

Each session offers practical, applicable knowledge that clinicians can immediately implement in their practice to improve outcomes for this unique patient population. The summit creates valuable opportunities for cross-disciplinary collaboration among specialists, primary care physicians, nurse practitioners, physician assistants and other healthcare professionals who encounter primary immunodeficiency cases.

An all access pass to the summit costs $250, which includes one complimentary night in Marriott Bethesda (Wednesday, Oct. 8), meals throughout the event and attendees will be able to claim CEU credits for their participation. The student and clinician still in residency rate is $100 and includes full access to the event, one complimentary night in Marriott Bethesda (Wednesday, Oct. 8), meals throughout the event, and attendees will be able to claim CEU credits for their participation. And, the local rate is $100 and includes all event sessions and activities. To register, go to web.cvent.com/event/620d5ba5-4f90-4ea7-b4d6-6b092880d0e6/regProcessStep1.

Funding support is available on a limited basis. For more information, contact events@primaryimmune.org.

2025 Medical Summit. Accessed at primaryimmune.org.


avoset
448mL
60.0
mL/h
EDIT
INFO
DISCARD AFTER USE
DISCARD AFTER USE

CAMPAIGN

CSL Launches First TV Ad for Hizentra

CSL Behring has launched the pharmaceutical industry's first-ever national commercial touting Hizentra as a self-administered treatment for primary immunodeficiency (PI) — for which the subcutaneous immune globulin (SCIG) product was initially approved in 2010. According to Priscilla Tavener, CSL's head of U.S. marketing for immunology and neurology, CSL chose to debut a TV ad after 15 years of Hizentra sales based on "the evolution of healthcare and the role that a patient plays within their decision making."

The 60-minute commercial features a woman with PI in a grocery store who is hesitant to touch her shopping cart, a self-checkout screen and fresh produce — all of which are depicted as being covered in germs. However, with Hizentra's help, the voiceover says the woman has "turned things around" as the woman spins around in a colorful swirl that morphs into the drug's logo.

Other scenes in the ad show her standing close to the fish counter and strangers and being able to pick up fruits and vegetables — with no more germs on display — as the voiceover describes how her "immune system is being restored," with a reduced risk of infections and steady immunoglobulin levels thanks to Hizentra.

The ad ends with the woman venturing beyond the grocery store to grab a cup of coffee with a friend at a café, as the voiceover encourages viewers to talk to their doctors about Hizentra.

"One of the things that was really exciting about the commercial is we really leaned into the insights that the patients shared with us about the everyday tasks that can be daunting to them as they go to a grocery store, as they go to their children's sports events," Taverna said. "So, we're really excited that the campaign really is very relevant to those patients, connects with them and encourages patients to talk to their physicians to see if Hizentra is the right option for them."

Park, A. CSL Behring's First Commercial Shows Hizentra Erasing Germ Concerns for Primary Immunodeficiency Patients. Fierce Pharma, May 21, 2025. Accessed at www.fiercepharma.com/marketing/csl-behrings-1st-commercial-shows-hizentra-erasing-germ-concerns-primary-immunodeficiency.

RESEARCH

Study of SCIG Via the Rapid Push Method Found Effective and Well-Tolerated

A recent study suggests subcutaneous immune globulin (SCIG) infusion via the rapid push method is effective, well-tolerated and feasible in large groups of patients with inborn errors of immunity (IEI).

In the study, the researchers assessed treatment efficacy, safety and quality of life in a large cohort of IEI patients who switched from intravenous immune globulin (IVIG) to SCIG. The observational study included 200 patients aged 1 to 65 years with IEI. SCIG (16.5%) was administered every seven to 10 days for at least 12 months via the rapid push method. Rate of infection, immunoglobulin G (IgG) concentration, adverse events and quality of life were assessed.

A total of 8,787 SCIG doses were administered during the study. The rate of infections (per person/month) during SCIG treatment was 0.05, which was significantly lower compared to 0.19 during the IVIG period ($p<0.001$). The median trough IgG was 6.9 g/L on IVIG, compared to 9.0 g/L during the first six months, and 9.2 g/L during the next six months on SCIG. Systemic reactions occurred in 12.4 percent of the IVIG infusions and 1.9 percent of the SCIG infusions. The total scores on quality of life summary assessments of physical and mental health were higher on SCIG therapy compared with IVIG ($p<0.001$). At the end of the study, 85.6 percent of the patients chose to remain on SCIG.

Avedova, A, Deripapa, E, Rodina, Y, et al. Prospective Multicenter Study of Treatment Efficacy, Safety, and Quality of Life in a Large Cohort of Patients with Inborn Errors of Immunity Receiving Subcutaneous Immunoglobulin. *Frontiers in Immunology*, Volume 16, 2025. Accessed at www.frontiersin.org/journals/immunology/articles/10.3389/fimmu.2025.1598491/abstract.

If you're an adult living with primary immunodeficiency (PI), ALYGLO™ can reduce the risk of infection from PI and its impact on your daily life.[1]
Based on a clinical study of 33 adults ages 17-70 in North America.[1]

0.03 SERIOUS INFECTIONS per patient year[1]

0.2 DAYS OF HOSPITALIZATION per patient year[1]

6 DAYS MISSED OF WORK OR SCHOOL per year[1]

INDICATION

ALYGLO™ is indicated for the treatment of primary humoral immunodeficiency (PI) in adults aged 17 years and older. This includes, but is not limited to, congenital agammaglobulinemia, common variable immunodeficiency (CVID), Wiskott-Aldrich syndrome, and severe combined immunodeficiencies.

IMPORTANT SAFETY INFORMATION

- **Thrombosis (blood clot formation) can happen with ALYGLO. Factors that increase this risk include advanced age, prolonged immobility, certain medical conditions, and cardiovascular risk factors.**
- **ALYGLO may affect the kidneys. In some cases, it can lead to acute renal failure or death.**
- **If you're at risk for blood clots or kidney problems, your doctor should give you ALYGLO at the lowest effective dose and infusion rate. Staying well-hydrated before treatment is essential.**
- ALYGLO is not suitable for people who have had severe allergic reactions to immune globulin or those with IgA deficiency and a history of hypersensitivity.
- If you experience any signs of hypersensitivity during the infusion, treatment should be stopped and epinephrine (an emergency medication) should be administered immediately.
- ALYGLO may cause hyperproteinemia, increased serum viscosity, and hyponatremia (low sodium levels).
- Aseptic Meningitis Syndrome (AMS) is a rare condition that can occur after receiving ALYGLO, especially with high doses or rapid infusion. Symptoms usually start within a few hours to 2 days after treatment. If AMS occurs, stopping ALYGLO usually leads to improvement within several days without lasting effects.
- Hemolysis, a breakdown of red blood cells, may occur. Some patients may experience delayed hemolytic anemia due to increased sequestration of red blood cells. Severe hemolysis-related kidney dysfunction or disseminated intravascular coagulation has been reported.
- Transfusion-Related Acute Lung Injury (TRALI) is a rare complication characterized by severe respiratory distress, pulmonary edema, and fever. Patients with TRALI may need oxygen therapy and ventilator support.
- ALYGLO is made from human blood, which may carry a risk of transmitting infectious agents (such as viruses).
- After receiving ALYGLO, some antibodies from the treatment may temporarily show up in blood tests. This could lead to misleading results, so your healthcare provider will consider this when interpreting lab results.
- Common side effects include headache, nausea/vomiting, fatigue, nasal/sinus congestion, rash, arthralgia, diarrhea, muscle pain/aches, infusion site pain/swelling, abdominal pain/discomfort, cough, and dizziness.

Reference: 1. ALYGLO Prescribing Information. GC Biopharma; 2023.

For more information about ALYGLO, talk to your doctor and see Brief Summary of Prescribing Information on next page.

0031-00-2024 5/2024

GC Biopharma

Alyglo™

immune globulin
intravenous, human-stwk
10% liquid

BRIEF SUMMARY OF PRESCRIBING INFORMATION
Please see full Prescribing Information at ALYGLO.com.

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 ALYGLO. 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. ALYGLO does not contain sucrose.**
- **For patients at risk of thrombosis, renal dysfunction or renal failure, administer ALYGLO at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.**

INDICATIONS AND USAGE

ALYGLO is a 10% immune globulin liquid for intravenous injection, indicated for the treatment of primary humoral immunodeficiency (PI) in adults. This includes, but is not limited to, the humoral immune defect in congenital agammaglobulinemia, common variable immunodeficiency (CVID), X-linked agammaglobulinemia, Wiskot-Aldrich syndrome, and severe combined immunodeficiency (SCID).

DOSAGE AND ADMINISTRATION

For intravenous use only.

Dose

Table 1 Recommended Dose

Dose	Infusion Number	Initial Infusion Rate	Maintenance Infusion Rate
300 - 800 mg/kg body weight every 21 or 28 days	For the 1st Infusion	1 mg/kg/min (0.01 mL/kg/min)	Double the infusion rate every 30 minutes (if tolerated) up to 8 mg/kg/min (0.08 mL/kg/min)
300 - 800 mg/kg body weight every 21 or 28 days	From the 2nd Infusion	2 mg/kg/min (0.02 mL/kg/min)	Double the infusion rate every 15 minutes (if tolerated) up to 8 mg/kg/min (0.08 mL/kg/min)

Significant differences in the half-life of IgG among patients with PI may necessitate the dose and frequency of immunoglobulin therapy to vary from patient to patient. Determine the proper dose and frequency by monitoring clinical response.

Measles Exposure

If a patient has been exposed to measles, consult with physician to administer an extra dose of IGIV as soon as possible and within 6 days of exposure. A dose of 400 mg/kg should provide a serum level > 240 mIU/mL of measles antibodies for at least two weeks.

If a patient is at risk of future measles exposure and receives a dose of less than 530 mg/kg every 3 - 4 weeks, then the dose should be increased to at least 530 mg/kg. This should provide a serum level of 240 mIU/mL of measles antibodies for at least 22 days after infusion.

Administration

- Monitor vital signs throughout the infusion. Slow or stop the infusion if adverse reactions occur. If symptoms subside, the infusion may be resumed at a lower rate that is comfortable for the patient.
- Ensure that patients with pre-existing renal insufficiency are not volume depleted. For patients at increased risk of renal dysfunction or thrombotic events, administer ALYGLO at the minimum infusion rate practicable, and consider discontinuation of administration if renal function deteriorates [*see Boxed Warning, Warnings and Precautions*].
- After administration, the infusion line may be flushed with either normal saline or 5% dextrose in water.

CONTRAINDICATIONS

ALYGLO is contraindicated in:

- Patients who have a history of anaphylactic or severe system reaction to the administration of human immune globulin.
- IgA-deficient patients with antibodies to IgA and a history of hypersensitivity [*see Warnings and Precautions*].

WARNINGS AND PRECAUTIONS

Hypersensitivity: Severe hypersensitivity reactions may occur[1]. In case of hypersensitivity, discontinue ALYGLO infusion immediately and institute appropriate treatment. Have epinephrine available for immediate treatment of severe acute hypersensitivity reactions.

ALYGLO contains trace amounts of IgA (≤ 100 mcg/mL). Patients with known antibodies to IgA may have a greater risk of developing potentially severe hypersensitivity and anaphylactic reactions. ALYGLO is contraindicated in IgA-deficient patients with antibodies against IgA or a history of hypersensitivity reaction [*see Contraindications*].

Thrombotic Events: Thrombosis may occur following treatment with ALYGLO[1]. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling central vascular catheters, hyperviscosity and cardiovascular risk factors. Thrombosis may occur in the absence of known risk factors.

Consider baseline assessment of blood viscosity in patients at risk for hyperviscosity, including patients with cryoglobulins, fasting chylomicronemia/markedly high triacylglycerols (triglycerides), or monoclonal gammopathies. For patients at risk of thrombosis, administer ALYGLO 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 [*see Boxed Warning, Dosage and Administration*].

Renal Failure: Renal dysfunction, acute renal failure, osmotic nephropathy, and death[1] may occur upon use of ALYGLO. Ensure that patients are not volume-depleted before administering ALYGLO. Monitor renal function and urine output periodically, especially in patients who are at higher risk of renal failure. Assess renal function, including measurement of blood urea nitrogen (BUN) and serum creatinine before the initial infusion of ALYGLO and at appropriate intervals thereafter. If renal function deteriorates, consider discontinuing ALYGLO. In patients who are at risk of developing renal dysfunction, because of pre-existing renal insufficiency or predisposition to acute renal failure (such as diabetes mellitus, hypovolemia, overweight, use of concomitant nephrotoxic medicinal products or age > 65 years), administer ALYGLO at the minimum infusion rate practicable [*see Boxed Warning, Dosage and Administration*].

Hyperproteinemia, Increased Serum Viscosity, and Hyponatremia: Hyperproteinemia, increased serum viscosity, and hyponatremia may occur in patients receiving ALYGLO. It is critical to clinically distinguish true hyponatremia from a pseudohyponatremia that is associated with or causally related to hyperproteinemia with concomitant decreased calculated serum osmolality or elevated osmolar gap. Such treatment aimed at decreasing serum free water in patients with pseudohyponatremia may lead to volume depletion, a further increase in serum viscosity, and a possible predisposition to thrombotic events[1].

Aseptic Meningitis Syndrome (AMS): AMS may occur with ALYGLO. AMS usually begins within several hours to 2 days following ALYGLO treatment. Discontinuation of treatment has resulted in remission of AMS within several days without sequelae[1].

AMS may occur more frequently with high doses (2 g/kg) and/or rapid infusion of ALYGLO. AMS is characterized by the following signs and symptoms: Severe headache, nuchal rigidity, drowsiness, fever, photophobia, painful eye movements, nausea, and vomiting. Cerebrospinal fluid (CSF) studies frequently reveal pleocytosis up to several thousand cells per cubic millimeter, predominantly from the granulocytic series, and elevated protein levels up to several hundred mg/dL, but negative culture results. Conduct a thorough neurological examination on patients exhibiting such signs and symptoms, including CSF studies, to rule out other causes of meningitis.

Hemolysis: ALYGLO may contain blood group antibodies that can act as hemolysins and induce *in vivo* coating of red blood cells (RBCs) with immunoglobulin, causing a positive direct antiglobulin test (DAT) (Coombs test) result and hemolysis[1]. Delayed hemolytic anemia due to enhanced RBC sequestration, and acute hemolysis, consistent with intravascular hemolysis, have been reported. Cases of severe hemolysis-related renal dysfunction/failure or disseminated intravascular coagulation have occurred following infusion of IGIV.

Hemolysis (cont.):

The following risk factors may be associated with the development of hemolysis following IGIV administration: High doses (e.g., 2 g/kg or more), given either as a single administration or divided over several days, and non-O blood group. Other individual patient factors, such as an underlying inflammatory state (as may be reflected by, for example, elevated C-reactive protein or erythrocyte sedimentation rate), have been hypothesized to increase the risk of hemolysis following administration of IGIV[1], but their role is uncertain.

Closely monitor patients for clinical signs and symptoms of hemolysis, particularly patients with risk factors noted above. Consider appropriate laboratory testing in higher risk patients, including measurement of hemoglobin or hematocrit.

If clinical signs and symptoms of hemolysis or a significant drop in hemoglobin or hematocrit have been observed, perform confirmatory laboratory testing, including direct antiglobulin test. If transfusion is indicated for patients who develop hemolysis with clinically compromising anemia after receiving ALYGLO (immune globulin intravenous, human-stwk), perform adequate cross-matching to avoid exacerbating ongoing hemolysis.

Transfusion-Related Acute Lung Injury (TRALI): Noncardiogenic pulmonary edema [Transfusion-Related Acute Lung Injury (TRALI)] may occur in patients administered ALYGLO[1]. TRALI is characterized by severe respiratory distress, pulmonary edema, hypoxemia, normal left ventricular function, and fever. Signs and symptoms typically appear within 1 to 6 hours following treatment. Patients with TRALI may be managed using oxygen therapy with adequate ventilator support.

Monitor patients for pulmonary adverse reactions. If TRALI is suspected, perform appropriate tests for the presence of antineutrophil antibodies and anti-human leukocyte antigen (HLA) antibodies in both the product and the patient's serum.

Transmissible Infectious Agents: Because ALYGLO is made from human blood, it 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. The risk of infectious agent transmission has been reduced by screening plasma donors and by including virus inactivation/removal steps in the manufacturing process of ALYGLO.

Report all infections thought by a physician possibly transmitted by ALYGLO to GC Biopharma USA, Inc. at 1-833-426-6426. Discuss the risks and benefits of its use with the patient before prescribing or administering this product.

Monitoring Laboratory Tests

- Periodic monitoring of renal function and urine output is particularly important in patients at increased risk of developing acute renal failure. Assess renal function, including measurement of blood urea nitrogen (BUN) and serum creatinine before the initial infusion of ALYGLO and at appropriate intervals thereafter.
- Because of the potential for increased risk of thrombosis with ALYGLO, consider baseline assessment of blood viscosity in patients at risk for hyperviscosity, including those with cryoglobulins, fasting chylomicronemia/markedly high triacylglycerols (triglycerides), or monoclonal gammopathies.
- If signs and/or symptoms of hemolysis are present after an infusion of ALYGLO, perform appropriate laboratory testing for confirmation.
- If TRALI is suspected, perform appropriate tests for the presence of anti-neutrophil antibodies in both the product and patient's serum.

Interference with Laboratory Tests: After infusion of immunoglobulin, the transitory rise of the various passively transferred antibodies in the patient's blood may yield positive serological testing results, with the potential for misleading interpretation. Passive transmission of antibodies to erythrocyte antigens (e.g., A, B, and D) may cause a positive direct or indirect antiglobulin (Coombs) test.

ADVERSE REACTIONS

The most common adverse reactions, observed in ≥ 5% of study subjects, were headache, nausea/vomiting, fatigue, nasal/sinus congestion, rash, arthralgia, diarrhea, muscle pain/aches, infusion site pain/swelling, abdominal pain/discomfort, cough, and dizziness.

Clinical Trials Experience: Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice.

In an open-label, single-arm, multicenter, non-randomized clinical trial, 33 subjects with primary humoral immunodeficiency received doses of ALYGLO ranging from 319 mg/kg to 817 mg/kg every 21 days or 28 days for up to 12 months.

The passive transfer of antibodies with IGIV administration may interfere with the response to live virus vaccines such as measles, mumps, rubella, and varicella. Immunizing physicians should be informed of recent IGIV therapy so that appropriate measures may be taken.

Twenty-eight subjects (85%) experienced a total of 145 temporally associated adverse reactions (adverse events that occurred during or within 72 hours after the end of an infusion) during the study. The temporally associated ARs were headache (13 subjects, 39%), nausea/vomiting (11 subjects, 33%), fatigue (6 subjects, 18%), nasal/sinus congestion (5 subjects, 15%) rash (4 subjects, (12%), arthralgia, diarrhea (3 subjects, 9% each), muscle pain/aches, infusion site pain/swelling, abdominal pain/discomfort, cough, dizziness (2 subjects, 6% each).

These are presented in Table 2. There were no deaths and no adverse reactions leading to withdrawal from the study.

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Table 2 Adverse Reactions* (ARs) (within 72 hours after the end of an ALYGLO infusion) in ≥ 5% of Subjects

Adverse Reactions (ARs)	No. of Subjects Reporting ARs (Percentage of Subjects) [N[1]=33]	No. of Infusions with ARs (Percentage of Infusions) [N[2]=427]
Headache	13 (39)	32 (7.5)
Nausea/vomiting	11 (33)	20 (4.7)
Fatigue	6 (18)	18 (4.2)
Nasal/sinus congestion	5(15)	5 (1.2)
Rash	4 (12)	4 (0.9)
Arthralgia	3 (9)	4 (0.9)
Diarrhea	3 (9)	3 (0.7)
Muscle pain/aches	2 (6)	7 (1.6)
Infusion site pain/swelling	2 (6)	6 (1.4)
Abdominal pain/discomfort	2 (6)	3 (0.7)
Cough	2 (6)	2 (0.5)
Dizziness	2 (6)	2 (0.5)

*Adverse events that occurred during or within 72 hours after the end of an infusion

[1] Total number of subjects

[2] Total number of infusions

Postmarketing Experience: Because postmarketing reporting of adverse reactions is voluntary and from a population of uncertain size, it is not always possible to reliably estimate the frequency of these reactions or establish a causal relationship to product exposure. The following adverse reactions have been identified and reported during the post-approval use of marketed IGIV products: **Blood and lymphatic system disorders:** leukopenia, hemolysis, pancytopenia; **Immune system disorders:** hypersensitivity (e.g., anaphylaxis), anaphylactic shock, anaphylactic reaction, anaphylactoid reaction, allergic reaction, angioedema, face edema; **Metabolic and nutritional disorders:** fluid overload, (pseudo) hyponatremia; **Psychiatric disorders:** agitation, confusion, anxiety, nervousness; **Nervous system disorders:** coma, loss of consciousness, seizures, (acute) encephalopathy, cerebrovascular accident, stroke, aseptic meningitis, migraine, speech disorder, paresthesia, hypoesthesia, photophobia, tremor; **Cardiac disorders:** myocardial infarction, cardiac arrest, angina pectoris, tachycardia, bradycardia, palpitations, cyanosis; **Vascular disorders:** hypotension, (deep vein) thrombosis, peripheral circulatory failure/collapse, hypertension, phlebitis, pallor; **Respiratory, thoracic and mediastinal disorders:** apnea, Acute Respiratory Distress Syndrome (ARDS), TRALI, respiratory failure, pulmonary embolism, pulmonary edema, bronchospasm, dyspnea, hypoxia, wheezing, cough; **Gastrointestinal disorders:** diarrhea, hepatic dysfunction, abdominal discomfort; **Skin and subcutaneous tissue disorders:** eczema, urticaria, rash (erythematous), dermatitis, pruritus, alopecia, Stevens-Johnson syndrome epidermolysis, skin exfoliation, erythema (multiform), dermatitis (e.g., bullous dermatitis); **Musculoskeletal and connective tissue disorders:** back pain, arthralgia, myalgia, musculoskeletal pain, muscle stiffness, pain in extremity, neck pain, muscle spasm; **Renal and urinary disorders:** acute renal failure, osmotic nephropathy, renal pain; **General disorders and administration site conditions:** injection-site reaction, chills, chest pain or discomfort, hot flush, flushing, flu-like illness, feeling cold or hot, edema, hyperhidrosis, malaise, asthenia, lethargy, burning sensation; **Investigations:** hepatic enzymes increased, oxygen saturation decreased, falsely elevated erythrocyte sedimentation rate, positive direct antiglobulin (Coombs) test.

DRUG INTERACTIONS

Clinical studies have not evaluated mixture of ALYGLO with other drugs and intravenous solutions. It is recommended that ALYGLO is administered separately from other drugs or medications which the patient may be receiving. Do not mix the product.

Transitory rise of the various passively transferred antibodies in the patient's blood after infusion of immunoglobulin may yield positive serological testing results, with the potential for misleading interpretation.

USE IN SPECIFIC POPULATIONS

Geriatric use: In patients over age 65 or in any patient at risk of developing renal insufficiency, do not exceed the recommended dose, and infuse ALYGLO at the minimum infusion rate practicable.

Reference: 1. ALYGLO Prescribing Information. GC Biopharma USA, Inc.; 2023.

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RESEARCH

Study Supports Development of Empasiprubart in MMN

Newly presented data from the Phase II ARDA study showed treatment with empasiprubart (Argenx), a C2-binding agent, was safe and reduced the need for intravenous immune globulin (IVIG) retreatment in patients with multifocal motor neuropathy (MMN). The efficacy and safety findings support the continued development of the therapy, which is currently being evaluated in the Phase III EMPASSION trial.

The analysis comprised 54 patients with MMN who were randomized to two cohorts of either empasiprubart (n=18) or placebo (n=9) for a 16-week period. Cohort 2 comprised more older patients with longer duration of disease and time since first IVIG treatment.

Results showed empasiprubart led to reduced IVIG retreatment risk versus placebo in both cohorts. Empasiprubart showed a safe and tolerable profile, and was well rated among treated patients: 55.6 percent and 66.7 percent of empasiprubart-treated participants in cohorts 1 and 2, respectively, described their condition as (very) much improved versus 11.1 percent and 22.2 percent of those on placebo.

In the proof-of-concept study, patients were receiving IVIG at baseline before switching to the study drug. At the last assessment, which included assessment after IVIG retreatment, median grip strength was improved among treated patients in comparison with placebo.

Study data provided proof-of-concept for EMPASSION, a larger-scale, Phase III trial of 100 patients with MMN. EMPASSION will use change from baseline in the 25-item Rasch-Built Overall Disability Scale for MMN as the primary end point. Following the double-blinded period, patients will have the ability to enter a 24-month open-label extension, where IVIG will not be permitted and all patients will receive the investigational drug. Other key secondary end points of the study include CFB in grip strength (most affected hand), modified Medical Research Council-14 sum score, Chronic Acquired Polyneuropathy-Patient-Reported Index total score, Patient Global Impression of Change actual value, and percent CFB in time to complete the 9-Hole Peg Test (dominant hand). Investigators also plan to assess safety of empasiprubart, pharmacodynamics, as well as change in grip strength, and Rasch-Transformed Fatigue Severity Scale score over time.

Meglio, M. Phase 2 ARDA Findings Support Development of Empasiprubart in Multifocal Motor Neuropathy. NeurologyLive, May 18, 2025. Accessed at www.neurologylive.com/view/phase-2-arda-findings-support-empasiprubart-multifocal-motor-neuropathy.

RESEARCH

Study Finds IVIG 10% Results in Significant Improvements in CIDP Relapses

In a retrospective study to evaluate the efficacy and safety of intravenous immune globulin (IVIG) 10% (GAMMAGARD LIQUID/Kiovig) in treating chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) relapses, investigators found that IVIG 10% effectively treated CIDP relapse and improved functional abilities, resulting in significant improvements in adjusted inflammatory neuropathy cause and treatment (INCAT) and rasch-built overall disability scale (R-ODS) centile scores.

The ADVANCE-CIDP 1 trial included adult patients with confirmed CIDP relapse (≥1-point increase in adjusted INCAT disability scores from pre-treatment baseline). Patients received an induction IVIG 10% dose (2 g/kg) followed by maintenance infusions at the same monthly equivalent dose of pre-randomization IVIG, three times weekly for six months. The primary outcome was the responder rate (≥1-point decrease in adjusted INCAT scores at treatment cessation versus pre-IVIG 10% baseline in patients receiving placebo in ADVANCE-CIDP 1). Other outcomes included the responder rate across all patients relapsing on facilitated subcutaneous immune globulin (fSCIG) 10% or placebo in ADVANCE-CIDP 1, time to functional improvement (≥1-point decrease in adjusted INCAT score) and change in adjusted INCAT scores and R-ODS centile scores from pre-IVIG 10% baseline.

Results showed 20 patients received IVIG 10% (four in fSCIG 10%-relapse group, 16 in placebo-relapse group). The responder rate was 100.0 percent (80.6%–100.0%) in the placebo-relapse group and 95.0 percent (76.4%–99.1%) in the overall-relapse population. The median time for functional improvement was 25 days. At treatment cessation, mean changes from pre-IVIG 10% baseline in adjusted INCAT and R-ODS centile scores were −1.9 and 12.9, respectively.

Results of IVIG 10% Therapy in ADVANCE-CIDP Trial for CIDP Relapse. Physician Weekly, April 30, 2025. Accessed at www.physiciansweekly.com/results-of-ivig-10-therapy-in-advance-cidp-trial-for-cidp-relapse.

RESEARCH

Subcutaneous Infliximab Found Effective with or Without an Immunosuppressant

A recent post hoc analysis showed that patients with Crohn's disease (CD) or ulcerative colitis (UC) who had achieved a clinical response to subcutaneous infliximab induction therapy in the LIBERTY trials and went on to maintenance/extension therapy showed no meaningful differences in efficacy outcomes regardless of whether induction infliximab was given as monotherapy or in combination with immunosuppressants. The analysis compared outcomes by baseline immunosuppressant use in patients receiving CT-P13 maintenance/extension therapy.

In the study, researchers looked at a variety of outcomes, including clinical remission, endoscopic remission and endoscopic response for CD, and clinical remission and endoscopic histologic-mucosal improvement for UC.

According to investigator Bruce E. Sands, MD, CT-P13, a subcutaneous form of infliximab showed superior efficacy over placebo for maintenance therapy up to one year for patients with moderate to severe CD and UC, and was shown to be effective and well-tolerated for up to two years in these patients.

In terms of safety, there were slightly more injection site reactions in the monotherapy group but no major differences between the two groups. There were higher rates of antidrug antibodies in patients on monotherapy, but this did not appear to translate into differences in efficacy over the two years of observation. The investigators concluded there were no meaningful differences in efficacy of maintenance therapy in patients with a clinical response to infliximab induction, either as a monotherapy or in combination with immunosuppressants, at weeks 54 and 102.

Smith, MJ. Subcutaneous Infliximab Found Effective With or Without an Immunosuppressant. Specialty Pharmacy Continuum, April 30, 2025. Accessed at www.specialtypharmacycontinuum.com/Clinical/Article/04-25/Infliximab-Maintenance-Therapy-Immunosuppressant/76964.

Your Voice Matters:

Practical Tips for Intentional Communication

Slowing down, thinking before you speak and saying what you really mean can help ensure your message is communicated effectively and cultivate mutual trust and respect.

By Rachel Colletta, BSN, CRNI, IgCN

MOST PEOPLE don't put much thought into how and why they communicate the way they do. In our daily lives, the way we talk at work and home often happens by chance. We rely on habits or assumptions, and often rush through conversations — so important messages can be misinterpreted or missed altogether.

It's important to remember our voices carry weight, especially when dealing with health challenges. Learning how to communicate better is an important part of managing health challenges well, especially when helping your friends, family and healthcare team understand your needs. Better communication skills help you exchange your feelings more clearly, and good listening skills build trust and understanding.

Some simple tips can help you communicate more thoughtfully. Small changes like picking your words carefully and showing genuine interest in what others say can transform how you connect with the people in your life. The following practical steps will make a real difference as you navigate your health challenges.

Speak with Purpose

Think about your most recent medical appointment. You might clearly remember how your physician explained your treatment options. The quality of your healthcare experience is significantly influenced by how well you understood their explanation, whether you felt comfortable asking questions and if you believed your concerns were genuinely acknowledged. Intentional communication goes beyond a simple exchange of words. This purposeful approach helps to convey messages with clarity and creates an effect.[1]

The essence of intentional communication lies in its purpose: staying conscious of our words.[2] People who communicate intentionally think about their words instead of speaking without thought. Picture intentional communication like a composer creating a symphony: Each note serves a purpose and adds to the overall harmony.[3] The way you deliver your message matters as much as the content itself.

Intentional communication needs three essential elements:

- Clear objectives: Your exact message must be clear.
- Audience awareness: You must know your listeners and adapt your style to them.
- Purposeful delivery: Your words and body language should match your message.

Communicating intentionally will give a clear and concise message that removes confusion and creates mutual understanding between people.[1] It builds trust by creating an open space where people feel heard and understood.[1] The concept might seem simple, but as intentional communication consultant Louise Altman explains, becoming skilled at intentional communication requires practice: "In many ways, skillful communicating is simple, but not easy. Breaking old habits requires conscious control."[2] Effectiveness requires regular practice.

> Thinking before speaking doesn't mean censoring yourself; instead, it helps ensure your words truly express what you want to say.

Why It Matters

Knowing how to communicate intentionally is critical for people managing chronic health conditions. Studies show that patient-provider communication plays a central role in disease management and helps patients understand their illness and treatment plans.[4] This type of communication serves several vital functions:

- Helps medical decision-making
- Improves self-management
- Creates healing relationships that increase well-being
- Offers emotional support in tough times
- Lets knowledge and information flow both ways

Further, research shows that active involvement in therapeutic communication leads to better patient self-management of conditions.[5] Poor communication due to language barriers can cause serious issues such as:

- Dissatisfaction with the care received
- Misdiagnosis of a condition
- Non-compliance with a treatment plan[5]

Patient-physician communication quality affects various patient-centered outcomes.[6] For example, good communication helps patients accept their illness(es) and understand risks and benefits of following treatment.[6]

Good communication forms the foundation of your health experience. Patients who take part in care decisions report better satisfaction, know more about their conditions and have realistic views about treatment benefits and risks.[7] These patients follow screening, diagnostic or treatment plans better and feel less anxious.[7]

Your intentional communication skills help you describe symptoms clearly, raise important questions and work with your healthcare team as equal partners. This partnership (called "shared decision-making") lets you and your healthcare providers exchange information, make decisions together and agree on the best treatment path.[7]

Start with Self-Awareness

Self-awareness builds the foundation of purposeful communication. It is important to understand what is happening in your own mind and body before you can share your thoughts with others effectively.

- *Notice your thoughts before you speak*. Your journey to better communication skills starts when you pay attention to your mind's activity before speaking. This might feel awkward at first; most of us speak without thinking about our thoughts.[8] The art of listening begins with the ability to listen to oneself.[9] This means you need to recognize the filters that shape your communication, including your experiences, beliefs, values and assumptions.

To practice noticing your thoughts:

- Pause before responding: Take a deep breath if you feel rushed to answer. This creates space between your thoughts and words.
- Identify your triggers: Know which situations or topics spark strong emotional reactions. Understanding your triggers helps you prepare for challenging conversations with healthcare providers.
- Think about your intentions: Ask yourself, "What do I want to achieve with this conversation?" This keeps your communication focused.

Thinking before speaking doesn't mean censoring yourself; instead, it helps ensure your words truly express what you want to say. This approach prevents misunderstandings, especially with medical professionals who need clear information about your symptoms.

• *Check in with your feelings.* Emotions shape communication significantly. Your frustration or anxiety about a medical appointment might affect how you speak. You need to recognize these emotions before they take over your communication.

> **Purposeful communication helps you express your needs clearly, particularly when facing health challenges.**

To check in with your feelings effectively:

- Name your emotions: Know exactly what you're feeling. Ask yourself if you are anxious, frustrated, hopeful or confused.
- Notice physical sensations: Look for signs like shoulder tension, racing heart or dry mouth.
- Accept feelings without judgment: Know that all emotions matter, which helps you respond thoughtfully.

This awareness gives you control over your reactions rather than letting them control you.

Patients with chronic conditions benefit even more from emotional awareness. Medical appointments often trigger intense feelings: fear about test results, frustration with treatment options or anxiety about explaining your symptoms. Your healthcare team communication improves when you understand these emotions.

Emotional awareness doesn't mean hiding feelings, but understanding them so they don't cloud your message. Acknowledging emotions builds more trust than ignoring them.

Your foundation for purposeful communication starts with self-awareness. This helps you express your needs clearly and listen more effectively to others.

Simple Ways to Practice

Your awareness of thoughts and feelings is just the beginning. The next step involves turning this awareness into action. A few simple techniques can help you have better doctor visits and less stressful daily conversations.

• *Use short and clear sentences.* Simple, direct communication works best. People often have trouble expressing themselves because they use too many words. Research shows you can communicate better by keeping your message concise while holding interest and covering the main points.

Here's how you can make your sentences clearer:

- Focus on one idea at a time: Share one thought before moving to the next instead of explaining everything together.
- Remove extra words: Ask yourself if you need 10 words when one will do. Even the most interested listener will drift away if your message rambles.
- Be specific about what you need: Instead of "I'm not feeling well," say "I've had a headache for three days that gets worse when I read."

This approach really helps during doctor appointments where time is limited. Healthcare providers value patients who describe their symptoms clearly and briefly.

• *Pause before you respond.* A moment of pause before speaking seems basic, yet it makes a huge difference. Studies show that pausing lets your mind control what comes out of your mouth and gives you time to organize your thoughts.

Pausing helps you in several ways:

- You get time to breathe first: Speaking without breaks makes you sound rushed and nervous. A small quiet moment helps you calm down and control your emotions.
- The pause also helps you avoid filler words like “um,” “ah” and “uh”: These words can cloud the true meaning of what you are trying to convey. Brief pauses work better than these fillers.
- Your listener also gets time to process what you’ve said: People need twice as long to understand your point as you need to say it. Without pauses, they might still think about your first point while you talk about something else.

Try this: Silently count to three before answering questions at your next medical appointment. Your answers will likely come out clearer and more thoughtful.

• *Choose words that match your feelings*. Words carry power, but many of us struggle with “feeling words” when describing emotional experiences. We often say “fine” or “good” when someone asks how we feel. These words don’t really describe emotions. The right words can help doctors understand your experience better. Instead of feeling “bad,” you might feel “frustrated,” “worried” or “discouraged” about your symptoms. This detail helps healthcare providers understand your physical and emotional state.

Your emotions provide valuable information. Describing feelings in words can actually reduce their intensity and make tough conversations easier. Research shows that putting strong emotions into words can lessen their impact, which helps during stressful medical discussions.

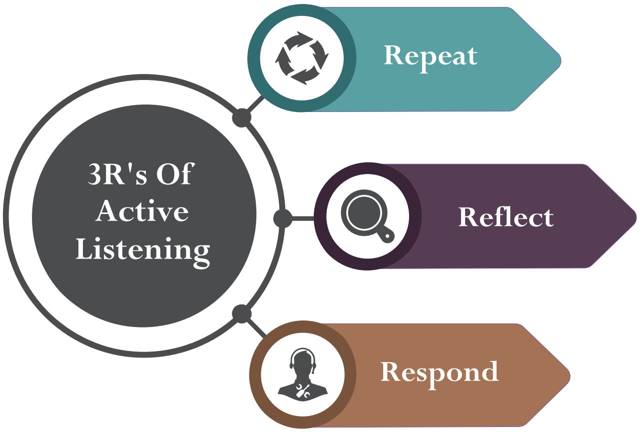
Next time you talk to your doctor, notice what you’re feeling, and name that emotion specifically. This practice creates better communication and builds trust with your healthcare providers.

Listen with Care and Attention

Communication works both ways. Speaking clearly represents just half of the picture, and listening is the foundation of meaningful conversations that people often overlook.

• *What active listening looks like*. Active listening goes beyond just hearing words. You need to focus on the speaker, understand their message and show that you’re involved. Patients with chronic illness benefit greatly when doctors, family and friends hear them out, which improves their care quality.

Active listening consists of several essential elements:



- Full attention: Put aside distractions such as phones or computers.
- Understanding the whole message: Pick up on both words and feelings.
- Patience: Let the speaker finish without interrupting.
- Open mind: Don’t jump to conclusions about what is being said.

You will feel more satisfied with your care when healthcare providers listen actively. The same applies to family members; their active listening helps patients feel supported as they manage their condition.

• *How to show you are really listening*. Your body language tells others if you are paying attention. Straightforward actions demonstrate that you care about the speaker’s words.

- Use supportive body language: Look at the person speaking, maintain eye contact and lean forward slightly. This shows your interest and involvement. A simple nod indicates you’re following the conversation.
- Ask helpful questions: Move beyond “yes/no” questions, and use open-ended ones that demonstrate your desire to understand.
- Reflect what you hear: Rephrase important points such as, “It sounds like the new medication reduces your pain but causes fatigue?” This helps ensure you’ve understood correctly.
- Avoid distractions: Keep your phone away and the TV off. These simple gestures show that the conversation matters to you.
- Show empathy through your expressions: Match your facial expressions with the speaker’s emotions. Express concern at the right moments, or smile when they share something positive.
- Listening doesn’t require perfect responses: Most people just want to know that you hear them.

For people with primary immunodeficiency (PI)

TURN PI ***AROUND*** WITH HIZENTRA

Actor Portrayal

Important Safety Information

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

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

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

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

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

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

Inform your doctor of any medications you are taking, as well as any medical conditions you may have had, especially if you have a history of diseases related to the heart or blood vessels, or have been immobile for some time. Inform your physician if you are pregnant or nursing, or plan to become pregnant.

Hizentra®
Immune Globulin Subcutaneous
(Human) 20% Liquid

Get the protection of Ig without the IV

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

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

LIVE IN ***STRENGTH***
WITH HIZENTRA

Scan for more reasons to switch

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

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

Ig, immunoglobulin; IVIg, intravenous immunoglobulin.

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

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

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

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

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

CSL Behring

Hizentra®
Immune Globulin Subcutaneous (Human) 20% Liquid

Important Safety Information (continued)

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

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

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

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

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

BRIEF SUMMARY OF PRESCRIBING INFORMATION

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

What is HIZENTRA?

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

Who should NOT take HIZENTRA?

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

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

CSL Behring

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www.CSLBehring.com www.Hizentra.com
USA-HPI-0134-APR2025

What are possible side effects of HIZENTRA?

The most common side effects with HIZENTRA are:

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

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

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

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

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

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

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

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

Based on April 2023 version.

Easy Exercises to Build Good Habits

You can't build better communication habits overnight. Simple exercises help you practice these skills until they become automatic. Here are two practical methods that fit right into your daily routine.

- *Daily five minute reflection practice*. A daily reflection practice is a simple yet powerful way to build self-awareness that serves as the life-blood of intentional communication. You only need five to 10 minutes each night to make a difference.[16]

Starting your own reflection practice is straightforward:

- Pick a time that works best, like during your bedtime routine.
- Choose a method you'll stick with (notebook, phone app or Google sheet).
- Ask yourself questions such as, "What happened today?" "How am I feeling?" and "Why am I feeling this way?"
- Look for patterns in your responses as time goes by.

This practice shouldn't feel like another task on your to-do list. Think of it as a chance to connect with your daily experiences and feelings.[16] Regular reflection helps you spot your communication patterns and areas you can improve.

- *Role-play simple conversations with a friend*. Role-playing gives you a safe space to practice communication skills before using them in real-life situations such as doctor appointments. This technique lets you try new skills in different scenarios while boosting your confidence.[17]

Here's how to try role-playing at home: Start by picking a scenario that matters to you — maybe explaining symptoms to a doctor or discussing treatment options with family. Next, assign roles with someone you trust. Act out the conversation naturally.[17]

The real value comes from the discussion afterward. Talk about what worked and what needs improvement. People with chronic illness find that practicing tough health conversations reduces their anxiety and leads to better outcomes.

Beginners often benefit from the "Active Listening Pairs" exercise. One person talks about a topic for a set time while the other listens quietly. The listener then summarizes what they heard to check their understanding.[1]

Small Steps, Significant Impact

Better communication begins with small steps that create significant impact. Purposeful communication helps you express your needs clearly, particularly when facing health challenges. Taking time to notice your thoughts and feelings before speaking can revolutionize your conversations with doctors, family and friends. Your self-awareness creates this foundation.

Clear, short sentences help others understand you better. A quick pause before responding gives you time to collect your thoughts. Doctors understand both your physical symptoms and emotional state better when you choose specific words that match your feelings.

Additionally, listening carries equal weight as speaking. You build stronger connections and better understanding by showing others you're truly hearing them through your body language, questions and focus.

Purposeful communication in your daily life gives you control over your health and strengthens your care team's relationships. These skills become habits through exercises like the five-minute reflection and role-playing conversations without overwhelming you.

Good communication doesn't require perfection. It needs practice and builds on progress. Every purposeful conversation takes you closer to being heard and understood. Your voice holds power — especially regarding your health and well-being.

Sources

1. Patrick, K. 17 Best Communication Games, Activities and Exercises for Employees in 2025. edstellar, Jan. 1, 2025. Accessed at www.edstellar.com/blog/communication-activities-games-exercises.
2. Altman, L. Communicating Intentionally — the Basics. Intentional Communication Consultants. Accessed at intentionalcommunication.com/communicating-intentionally-the-basics.
3. Menguin, J. What Is Intentional Communication? Strategic Learning. Accessed at www.strategiclearning.asia/intentional-communication.
4. Iroegbu, C, Tuot, DS, Lewis, L, et al. The Influence of Patient-Provider Communication on Self-Management Among Patients with Chronic Illness: A Systematic Mixed Studies Review. *JAN,* 2024 Sept 28;81(4):1678-1699. Accessed at onlinelibrary.wiley.com/doi/10.1111/jan.16492.
5. Ameworwor, ER, Amu, H, Dowou, RK, et al. Exploring Therapeutic Communication in Managing Chronic Non-Communicable Diseases: A Mixed-Method Study in Ghana. *Archives of Public Health*, 2024 Mar 14;82(1):36. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC10938704.
6. Sharkiya, SH. Quality Communication Can Improve Patient-Centred Health Outcomes Among Older Patients: A Rapid Review. *BMC Health Services Research*, 2023; 23:886. Accessed at bmchealthservres.biomedcentral.com/articles/10.1186/s12913-023-09869-8.
7. Krist, AH, Tong, ST, Aycock RA, et al. Engaging Patients in Decision-Making and Behavior Change to Promote Prevention. Studies in Health Technology Informatics, 2017; 240:284-302. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC6996004.
8. University of Cincinnati Press. Academic Oral Communication for International Students: Emotional Awareness as a Form of Communication. Accessed at ucincinnatipress.pressbooks.pub/oralcommunication/chapter/emotional-awareness-as-a-form-of-communication.
9. Civico, A. How Self-Awareness Leads to Effective Communication. Psychology Today, April 21, 2014. Accessed at www.psychologytoday.com/us/blog/turning-point/201404/how-self-awareness-leads-effective-communication.
10. Calm. How (and Why) to Think Before You Speak: 12 Mindful Tips. Accessed at blog.calm.com/blog/think-before-you-speak.
11. HSI Employee Training and Development. Communicating with Emotional Intelligence. Accessed at hsi.com/blog/communicating-with-emotional-intelligence-eq.
12. 4 Ways Self Awareness Makes You a Better Communicator. ASAP, April 21, 2022. Accessed at www.asaporg.com/communication/4-ways-self-awareness-makes-you-a-better-communicator.
13. Powell, L. 3 Important Lessons on Mindful Conversation. Mindful, Dec. 2, 2022. Accessed at www.mindful.org/can-we-talk.
14. Upskillist. How Emotional Awareness Shapes Communication Styles. Accessed at www.upskillist.com/blog/how-emotional-awareness-shapes-communication-styles.
15. Vodianoi, M. Using Emotional Intelligence to Improve Communication. DDI, Jan. 4, 2024. Accessed at www.ddiworld.com/blog/emotional-intelligence-and-communication.
16. Janssen, A. How Daily Reflection Practice Cultivates Self Awareness and Joy. Ashley Janssen Consulting, Aug. 25, 2021. Accessed at ashleyjanssen.com/how-a-daily-reflection-practice-cultivates-self-awareness-and-joy.
17. Bosco, P. Role-Playing: A Fun and Effective Way to Boost Your Communication Skills. LinkedIn, May 26, 2023. Accessed at www.linkedin.com/pulse/role-playing-fun-effective-way-boost-your-skills-preetham-bosco.

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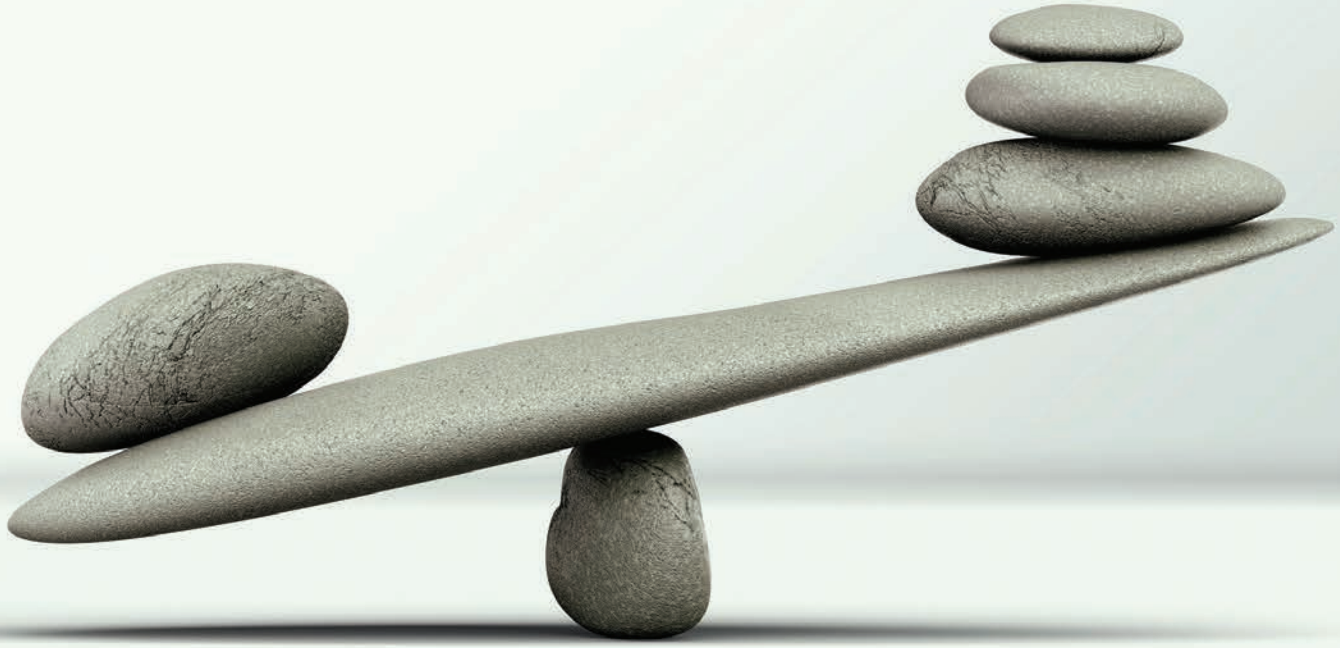
Pacing Your Activities for a Balanced Life

By determining how much energy daily activities require using a sizing scale, you can plan your days to better manage your energy levels.

By Pamela Rose



IF THERE’S one thing that most chronic health challenges have in common, it’s fatigue. As a fatigue coach, I see people with a variety of health diagnoses, most of whom struggle with this ailment. Although it might not be the only symptom someone is experiencing, I frequently hear that it is the one symptom stopping them from living a better quality of life — because if you don’t have as much energy as you would like to have, it is very difficult to get anything done, let alone the things that bring you joy and pleasure.

If you’ve been feeling fatigued for a while, and your previous approaches haven’t helped, this probably shows you that something needs to change.

While there are no quick fixes or miracle cures for fatigue, one thing comes close: pacing. Pacing means figuring out and implementing helpful approaches to better manage your energy throughout the days and weeks. Energy management is unique to everyone. Everyone’s life is different, so everyone’s approach to it needs to be a little bit different. I help patients figure out how to make an energy management plan that works best for them — and it can be truly transformational.

While everyone’s pacing plan will be different, there is a framework that can be shaped to fit anyone’s life. That framework will help people start to figure out what works for them, as well as show how helpful pacing and energy management can be.

Figuring Out Your Energy Management Approach

I know it sounds a little unhelpful to say that the thing that’s supposed to improve your energy levels will feel tough at first, but the harsh reality is that it needs to be. If you’ve been feeling fatigued for a while, and your previous approaches haven’t helped, this probably means something needs to change, and change can feel a bit tough at first. But in this case, it’s worth it. You probably need to give more detailed thought to your days, as well as make some difficult priority calls. That is not always easy to do. But once you realize that boundaries allow you to feel better most days, you will find it easier to stick to them. Drilling down the details of your life can help uncover what matters most to you, which will help you make meaningful lifestyle adjustments.

One reason people find this task difficult is because they are still hoping their health issue will disappear. They think, “If I ignore it, maybe it’ll go away.” And that’s understandable, of course. But it’s important that you find a way to accept your reality and to funnel the energy from unhelpful feelings such as denial and resistance into helpful ones such as determination and resolve to move forward.

If you’re recognizing that this is something you have struggled with, here’s a suggestion: Why not try doing things differently just for a couple of weeks? Read this article, look up other helpful resources, choose two or three things to do differently and see how it goes. Chances are you will have experienced at least some benefits to how you’ve felt and how things have gone. And this is all your brain needs to decide to help you stay focused on these positive changes.

My Fatigue Journal

Keep track of activities you do during the day and how fatigued you feel after doing them.

Fatigue Score: 0 = no fatigue; 3 = some fatigue; 5 = moderate fatigue; 8 = substantial fatigue; 10 = extreme fatigue

Date: August 26, 2025

Activity	Time Spent	Fatigue Score	Notes
Got ready for the day	40 minutes	3	Showering takes effort, but it also rejuvenates me. I feel more fatigued on days I discover I don't have anything clean to wear.
Made breakfast	5 minutes	2	Eating oatmeal, fruit and coffee for breakfast every day makes it easy.
Drove to work	8 minutes	1	I'm lucky my office is close to home! Short commute.
Interviewed applicants	3 hours	7	We had a lot of applicants for an open position. I spent the whole morning in interviews.
Attended mandatory departmental lunch meeting	60 minutes	5	Lots of updates and changes to implement.
Went to a medical appointment	60 minutes	8	Saw the doctor for a new bothersome symptom. I was nervous about it, but it turns out it's common and easy to treat.
Performed typical work duties	3 hours	6	My fatigue increased as the day wore on.
Drove home	10 minutes	4	There was a road closure on my normal route home today, so I had to use an alternate route.
Walked the dog	30 minutes	6	It was great to be outside and get some exercise, but the dog is not well-trained yet. It's hard to take him with me on my walks!
Cooked/ate dinner	45 minutes	5	I like cooking, but I'm tired of making the same thing over and over again. I don't have the brainpower to think about what else to make.
Listened to my husband tell me about his day	20 minutes	4	I want to hear how my husband's day went, but it's hard to focus my attention on him while I'm also trying to cook.
Started a load of laundry	5 minutes	8	By the end of the day, I'm too tired to fold laundry, but not folding it mentally exhausts me. It's a terrible cycle!
Picked up a prescription	20 minutes	7	I forgot to do this on my way home from work. Thankful for medicine; unhappy I had to run out at night to pick it up.
Answered a phone call from my daughter	15 minutes	3	It's always nice to hear my daughter's voice. She's having trouble at work, so she called for some advice. I didn't know what to tell her.
Made a cup of tea and read my book	30 minutes	0	My favorite way to relax.

Reflection:

- Do laundry once a week on the same day.
- Don't schedule appointments on days with several meetings.
- Ask someone else to walk the dog. Better yet, hire a dog walker!
- Make room in the budget to get take-out on days I have a medical appointment.

Create Your Personal Energy Sizing Scale

I talk to many people who have attempted to crack pacing on their own, but didn't stick to their plan because they were too busy or life placed too many other demands on their time. It was another thing to have to do on top of a day that felt too full already. On further questioning, it often becomes clear that they have previously seen pacing as just another thing they had to tackle on top of a to-do list that already felt quite overwhelming. However, developing a pacing plan is the tool they need to use to get that to-do list done!

The first thing to do is identify your unique energy sizing scale. You want to give the tasks you do in a given day some sort of shape and size based on how much effort it takes you to perform them. List nuances that can lend insight into your situation. (For example, does "grocery shopping" mean physically visiting the store and shopping; ordering groceries online and driving to pick them up; or ordering grocery delivery? Be specific.) Note: You shouldn't assume that time spent on the activity is the only element that defines how much energy something is going to need; you can get into much more helpful detail than that. (For example, grocery shopping can be mentally exhausting due to the extra thought that might need to go into finding food to accommodate special diets or fit into a tight budget.)

Using whatever sizing scale you want (letters, numbers, even colors), start to think about which big energy tasks and lower-energy tasks you do each day or week.

Using whatever sizing scale you want (letters, numbers, even colors), start to think about which big energy tasks and lower-energy tasks you do each day or week. This might feel so obvious that it seems like a pointless exercise, but thinking about this will start to show you how useful it can be. Give some curious thought to the differences between doing a task:

- for the first time as opposed to the 20th time (e.g., driving to work using a route you've never driven before).
- that you find easy (it's matched to your skill set) versus one you find difficult (e.g., helping your child do his or her English homework compared to helping with math homework).
- that you enjoy doing versus something you really don't want to be doing (e.g., a 20-minute phone chat with a dear friend rather than a 20-minute call to discuss your taxes).

Once you've started to give detailed thought to sizing tasks, it will help you spot a day that is shaping up to be particularly effortful. When that happens, think about whether you need to make some important priority calls — perhaps postponing a task or appointment — or think about how you can make the rest of the day as simple as it can be.

Many people struggle with this sizing concept because they feel their tasks can be different sizes depending on the day they do them and how they're feeling. (For example, they may have energy to go grocery shopping on Monday, so it feels like a small task then; by Friday, they are exhausted and grocery shopping feels like a big task.) However, in reality, they likely have not found their comfortable energy level yet. Once you identify a steady amount of energy that you can commit to using each day, your tasks will feel much more consistent in size. This is a great way to spot that you're starting to pace well!

Shape Your Days in Advance

The idea of planning or scheduling your day in detail can feel quite overwhelming and restrictive. But the most successful energy management approaches involve some amount of up front thought and decision-making.

If the thought of planning and scheduling feels too onerous for you, pick another word! Think about "designing," "shaping" or "creating" your days. That small shift can make it feel more appealing to do at the beginning of your day, which is a great start. However you decide to approach it, giving some thought to what and when you need (or want!) to do each day is the key to better managing your energy levels.

PAMELA ROSE is a fatigue coach supporting people around the world to better manage their fatigue-related challenges. She provides very real and practical guidance to her clients linked to behaviors that will start to make a noticeable difference. Based in the UK, she holds a Level 5 diploma in Performance Coaching and is a member of the National Council of Integrated Psychotherapists.

How Fitness Can Improve Daily Function

Consistent, moderate exercise is good for everyone, and it can even make life a little bit easier for people with chronic illness.

By Jim Trageser

PERHAPS NO field of human health is as littered with urban myths as physical fitness. Workout fads and trendy diets change as often as the weather, and the accepted "wisdom" all too often turns out to be medically inaccurate.

Two of the most prevalent fitness myths that might prevent those with a chronic illness from enjoying the benefits of a well-designed workout routine are 1) exercise weakens your immune system and 2) you have to push through the pain to achieve the benefits of exercise.

While there is some evidence that over-exercise can temporarily weaken the immune system, ongoing research confirms that moderate exercise does not impair the immune system and also offers proven functional and emotional benefits. You can (and should!) learn how to exercise at a level that's right for you: It can greatly improve your quality of life by increasing your range of motion and reducing pain you experience as you go about your everyday life.[1]

The ‘Open Window’ Hypothesis

Why is exercise thought to weaken the immune system? The idea comes from a 1990 survey conducted by researchers at Loma Linda University who asked participants in the Los Angeles Marathon to self-report any symptoms of infection following the race. Based on the runners’ responses, the researchers published a study arguing that training for and participating in a marathon increased the odds of contracting an infectious disease.[2]

Subsequent studies measured specific immune factors in elite-level athletes following training or competition and found that in the hours following extreme exertion, there were measurable changes to the immune system. In addition, there is substantial evidence showing that respiratory infections are the leading reported cause of lost training days among both world-class athletes and elite military personnel. The combination of the studies and the lost training days resulted in the hypothesis that exercise creates a post-exertion “window” of opportunity for infection.[3] As reported in the mainstream media, this evolved into the idea that exercise weakens the immune system.

However, in the decades since that first study, other studies have found that while the levels of specific cells and antibodies may fluctuate before and after heavy exertion, there is little evidence that normal exercise diminishes the immune system as a whole.[4] In fact, not only does moderate exercise *not* damage the immune system, recent research suggests that it *benefits* people with compromised immune systems.[5]

When Exercise Isn’t Easy

However, people with chronic illness often face everyday challenges that make prioritizing exercise more difficult. Cedric X. Bryant, PhD, FACSM, fellow of the American College of Sports Medicine knows this firsthand. A Penn State-trained lifelong fitness professional and advocate, Dr. Bryant found himself facing his own physical challenges after a mild case of COVID-19 led to severe post-COVID arthritis. “It got to where I couldn’t hold anything in my hands,” he recalls. He was even unable to grip the steering wheel of his car for a time. “For someone whose whole life is about movement, this was a shock,” he adds.

Dr. Bryant, whose mantra is “Some activity is better than none, and more is better than some!” says that everyone, no matter their medical condition, should try to perform as much exercise as they can.[6] “The mental and emotional benefits are profound — not only do [people] get benefits from a neurochemcial perspective, but also just being able to do things without discomfort causes them to feel better about their capabilities,” he explains. Chronic illness can disrupt daily life, making everyday tasks of living harder. Regaining function can be a huge morale boost.

While his condition has mostly resolved, Dr. Bryant says his bout with arthritis caused him to adjust his own approach to exercise, and he recommends that people with conditions that affect mobility such as lupus, scleroderma or rheumatoid arthritis talk to their doctor(s) before starting

For More Information

Exercise Is Medicine
(www.exerciseismedicine.org)

Hosted by the American College of Sports Medicine, this site offers resources for physicians on integrating fitness into patient care and features the “Rx for Health Series” of brochures with specific exercise tips for patients facing dozens of different diagnoses.

The National Library of Medicine
(medlineplus.gov/ency/article/007165.htm)

Part of the U.S. National Institutes of Health, this website offers information about exercise and immunity. It includes graphics that show how exercise affects different body parts and links to other pages with more information on exercising.

The Arthritis Foundation
(arthritis.org)

This site recommends a series of exercises to maintain joint flexibility and strength. Visit their website and search for “exercise.”

U.S. Registry of Exercise Professionals (USReps.org)

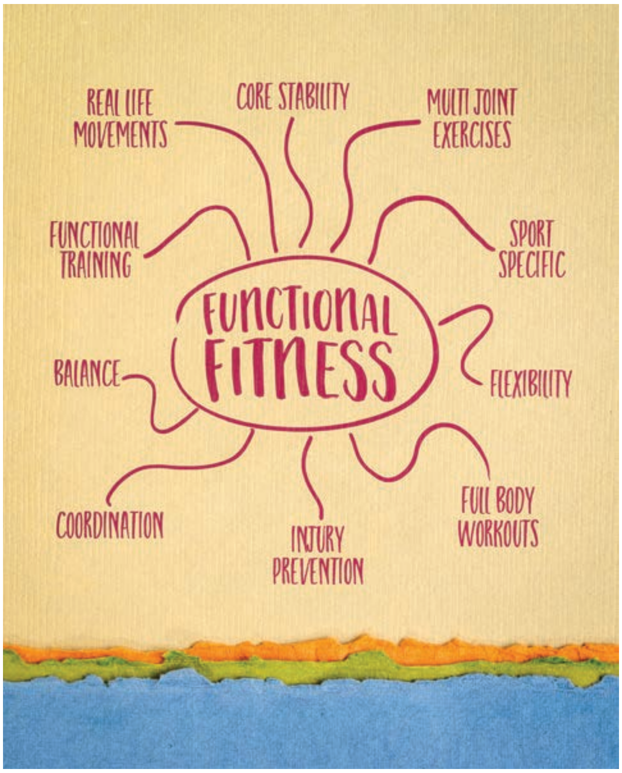
This site allows visitors to sort by ZIP code and specialty, one of which is exercise physiologist/medical exercise. Working with your physician and a qualified trainer from that database should get most folks off to a good start.

any new exercise routine. "Exercise must be approached with care and caution to avoid excessive fatigue, infections or even exacerbating [a] current condition. It's important that [patients] get some good guidance on how to approach exercise safely and smartly. They have to start by consulting their healthcare provider: They're the ones who are going to have the best insights regarding the condition," he says.

Patients may also consider seeking professional guidance when designing their exercise plans so they avoid any obvious missteps. "They want to make sure they're working with a licensed professional who's gone through a quality certification," he says. "I would look for someone who's on the U.S. Registry of Exercise Professionals — USReps.org. Those individuals have gone through a reasonable vetting process."

It's Not a Competition

If you are ready to begin exercising, Dr. Bryant urges patients to keep front of mind that your goal is to improve your quality of life — not to impress others. "It's important not to be real competitive — think about, from the philosophy of pharmacology, the concept of the 'minimal effective dose.'"



When exercising, also be conscious of respiratory strain, joint pain and fatigue, and be OK with calling it a day when you experience those. The myth of "pushing through the pain" came to our culture via the bodybuilding subculture, and bodybuilding isn't the goal of moderate exercise. Dr. Bryant says that for patients with an immunological disorder, it's more important to listen to your body and back off when it's telling you it has hit its limit: "It's important to avoid excessive intensity or duration to avoid suppression of immune system function." It's also important to avoid exercise during flare-ups, he says.

Also, what you do away from the gym is just as important to the success of your workouts: Maintain appropriate hydration and nutrition. For those with a chronic illness who may not have worked out in a while, Dr. Bryant says that good eating habits are essential because exercise will expend more energy than your body is used to.

Dr. Bryant also says to make sure to take stock of the environment you'll be working out in. "Be careful and prioritize proper hygiene to reduce the risk of infections," he cautions. "As much as possible, exercise in a clean, well-ventilated environment. Practice handwashing and disinfect exercise equipment." Exercising outdoors is often ideal for people who are immunocompromised, but if that is not practical, consider heading to the gym when it is less crowded to allow yourself more time to disinfect the equipment and reduce the amount of germs to which you are exposed.

Best Types of Exercise

Aerobic conditioning, strength training and flexibility exercises are beneficial for people with chronic illnesses.

- *Aerobic conditioning*. Dr. Bryant recommends exercising for 30 minutes three to five times a week at a low to moderate intensity. Low-impact activities such as walking, cycling (either stationary or outside) or swimming in a clean, well-maintained pool are good choices. Low-impact aerobics (elliptical machines or seated cardio exercises for those who have mobility limitations) are also good options. Just make sure you are able to talk while exercising. Back off if talking becomes a challenge while exercising. "It's OK to split it up into smaller periods, what I like to call 'exercise snacks' that add up to a full meal," he says.
- *Resistance and strength training*. Dr. Bryant says these make good additions to an exercise routine because they help maintain muscle mass and bone health. Aim for two to three times per week, reserving at least 48 hours for recovery between

sessions. "Again, focus on the 'minimal effective dose' — keep to light to moderate resistance. You should be able to do at least eight reps with good form to a max of 15. If you can do 15 reps without strain and in good form, then gradually increase the load to continue experiencing improvement."

Depending on your specific condition and your physician's guidance, consider body weight squats, modified pushups, resistance bands, light dumbbells and even weight machines, if you have access to them. Don't get caught up in chasing the fanciest or most expensive options, Dr. Bryant cautions. Much of the fitness industry is built around offering lots of shiny objects to catch our attention. "The important thing to remember is our muscles are referred to as 'motor fibers,' not 'sentient fibers.' The muscle doesn't care what equipment we use! Body weight and inexpensive tools can address resistance-training needs," he explains. Fitness goals can even be accomplished within our existing daily chores. "Even functional activities — carrying objects" are helpful. However, as Dr. Bryant cautions, "Think about any kind of joint pain or muscle weakness, reduce the resistance and focus on range of motion."

> **If you are ready to begin exercising, Dr. Bryant urges patients to keep front of mind that your goal is to improve your quality of life — not to impress others.**

- *Flexibility exercises.* Another low-impact form of exercise that can be beneficial in improving daily function is flexibility and mobility training, which is something you can pursue on most days. Dr. Bryant says it can involve everything from general stretching to dynamic movement. Tai chi is a good example. However, choosing a safe location to perform this sort of exercise is important, he says: "The only caveat is to make sure this is performed in a low-risk environment hygienically." Outdoor locations are usually a suitable option. Patients with balance issues should use a chair for support.

However, modifying workouts to support your unique challenges is important. In both aerobic exercise and strength training, Dr. Bryant recommends adhering to proper breathing. "Exhale with effort," he said, and avoid breath-holding, which can temporarily cause your blood pressure to rise, leading to dizziness or fainting. Also, patients treated with intravenous immune globulin therapy may also have additional challenges in designing an exercise regimen: "Some may experience heat sensitivity, so try to exercise in a cool environment and avoid prolonged exposure to direct sunlight." Keep these caveats in mind, but don't let them keep you from exercising.

- *Functional exercises.* Moving your body in a way that mimics the motion of everyday activities such as squats, lunges, push-ups and deadlifts strengthens the muscles and supports the joints you use when you sit down, climb stairs, push lawn mowers or grocery carts or pick up heavy grocery bags. Incorporating these movements as part of your strength training will help make everyday activities of living easier to manage and help prevent injury.[7]

Invest in Better Health

Regular exercise is important for living the healthiest version of your life as possible. Incorporating it into your routine can be especially challenging when chronic illness makes it more difficult. However, a combination of aerobic conditioning, strength training, flexibility and functional exercises can make your life a little easier by making you stronger, more limber and better able to perform everyday tasks. While fitness fads come and go, consistently devoting a moderate amount of time to exercise that works for you will never go out of style.

References

1. Mayo Clinic. Exercise and Chronic Disease: Get the Facts. Accessed at www.mayoclinic.org/healthy-lifestyle/fitness/in-depth/exercise-and-chronic-disease/art-20046049.
2. Nieman, D, Johanssen, L, Lee, J, and Arabatzis, K. Infectious Episodes in Runners Before and After the Los Angeles Marathon. *The Journal of Sports Medicine and Physical Fitness*, 1990 Sept;30(3):316-28. Accessed at pubmed.ncbi.nlm.nih.gov/2266764.
3. Coleman, A. Does Exercise Weaken Your Immune System? Training Peaks blog. Accessed at www.trainingpeaks.com/blog/does-exercise-weaken-your-immune-system.
4. Campbell, J, and Turner, J. Debunking the Myth of Exercise-Induced Immune Suppression: Redefining the Impact of Exercise on Immunological Health Across the Lifespan. *Frontiers in Immunology*, 2018 April 16;9:648. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC5911985.
5. Simpson, R, Campbell, J, Gleeson, M, et al. Can Exercise Affect Immune Function to Increase Susceptibility to Infection? *Exercise Immunology Review*, 2020;26:8-22. Accessed at pubmed.ncbi.nlm.nih.gov/32139352.
6. American Council on Exercise. Cedric X. Bryant profile. Accessed at www.acefitness.org/about-ace/our-team/executive-team/cedric-bryant.
7. HiTone Fitness. Funtional Movement Exercises That You Should Add to Your Routine, May 14, 2024. Accessed at www.hitonefitness.com/functional-movement-exercises-that-you-should-add-to-your-routine.

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

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

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

Count the reasons

to ask your care team about cutaquig

1
hour or less to
complete infusion*

2
or fewer
infusion sites†‡

3
flexible dosing
schedule options§

Not an actual patient.

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

INDICATIONS AND USAGE

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

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

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

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

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS

See full Prescribing Information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin products, including CUTAQUIG. Risk factors may include advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **For patients at risk of thrombosis, administer CUTAQUIG at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk of hyperviscosity.**

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

CUTAQUIG can cause the following serious reactions:

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

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

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

What should I know while taking CUTAQUIG?

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

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

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

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

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

The most common side effects of CUTAQUIG are:

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

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

- Mild or moderate pain
- Redness
- Itching

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

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

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

CUTAQUIG® is a registered trademark of Octapharma AG.

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

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Distributed by Pfizer Labs, Division of Pfizer Inc.

March 2023

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

CONSUMER BRIEF SUMMARY

(CUTAQUIG: *cute-ah-quig*)

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

What is CUTAQUIG?

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

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

WARNING: THROMBOSIS

See full Prescribing Information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin products, including CUTAQUIG. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling central vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **For patients at risk of thrombosis, administer CUTAQUIG at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk of hyperviscosity.**

Who should NOT use CUTAQUIG?

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

Tell your healthcare provider if you:

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

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

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

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

What should I tell my healthcare provider before using CUTAQUIG?

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

Tell your healthcare provider:

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

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

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

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

- Mild or moderate pain
- Redness
- Itching

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

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

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

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

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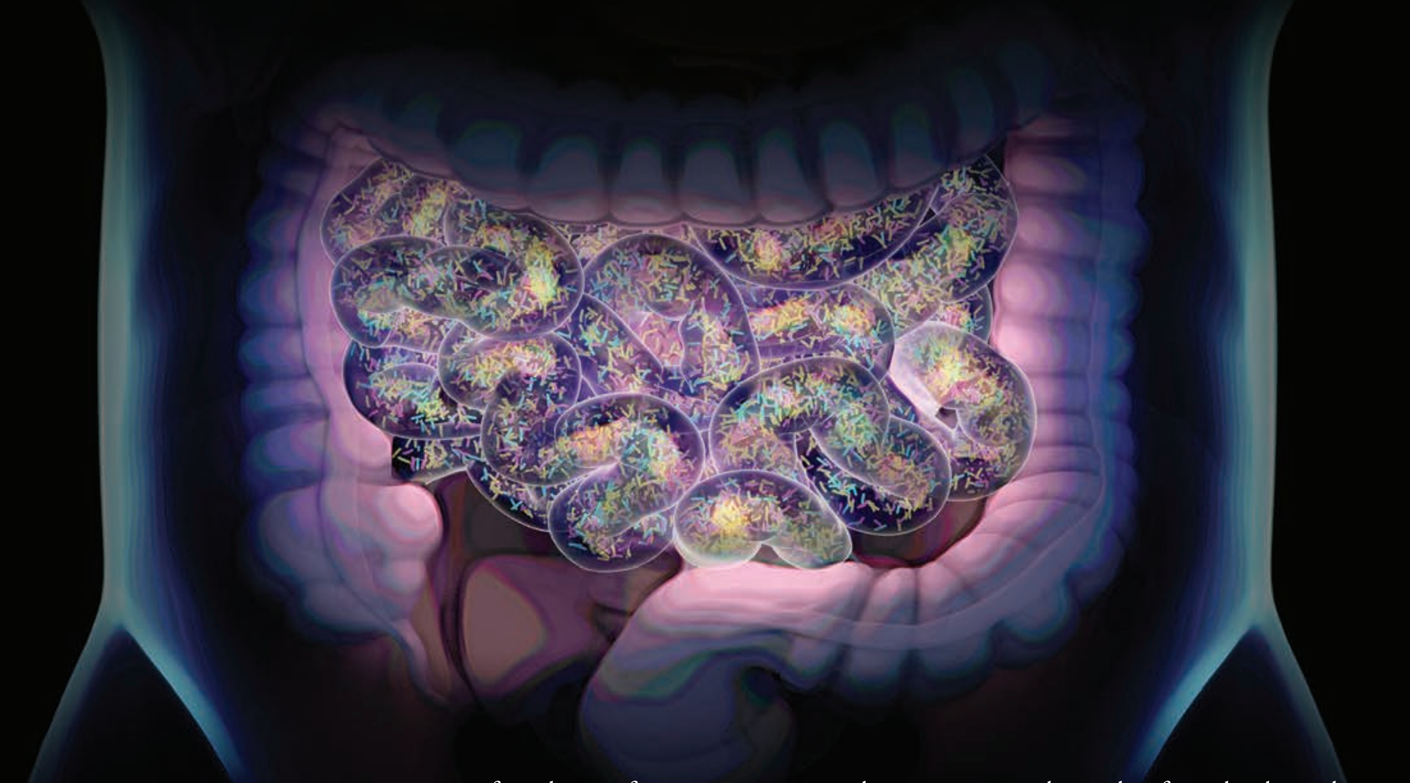
How Medications Affect Your Microbiome

Our guts are home to trillions of microbes, and all are vital for keeping our bodies healthy. While diet and lifestyle get most of the attention, common medications can significantly disrupt the balance in this complex ecosystem, often in ways we don't expect.

By Trudie Mitschang



FOLLOWING A ROUTINE course of antibiotics for a respiratory infection, Susan experienced persistent cramping, diarrhea and fatigue. While the original infection had cleared, the unintended disruption to her gut microbiota had unpleasant lingering side effects, triggering her to reach for additional medications that ultimately made the problem worse. Sound familiar? The frustrating fact is, from antibiotics to antacids, everyday medications we take to combat minor infections and maladies can sometimes do as much harm as good.

A study from the University Medical Center Groningen and the Maastricht University Medical Center, both in the Netherlands, found evidence to suggest that many frequently used drugs can significantly impact the gut microbiome and disrupt the delicate balance of essential bacterial populations.[1] The research investigated the effect of 41 common types of prescription drugs, comparing the results of people who took them with those who did not. They also looked at the effects of individual medications versus combinations of drugs.

Findings uncovered that out of 18 common drug categories, several appeared to have the strongest impact on bacterial balance in the gut: proton pump inhibitors (PPIs), which reduce the production of stomach acid; antibiotics, which fight bacterial infection; metformin, prescribed to manage the symptoms of type 2 diabetes; and laxatives, used to treat constipation.

"We already know that the efficiency and the toxicity of certain drugs are influenced by the bacterial composition of the gastrointestinal tract, and that the gut microbiota has been related to multiple health conditions," said lead researcher Arnau Vich Vila. "Therefore, it is crucial to understand the consequences of medication use in the gut microbiome."[1]

The Digestive Downside of Proton Pump Inhibitors (PPIs)

If you've ever reached for a Tums after a spicy meal or taken a PPI for heartburn, you're not alone. These medications are helpful for treating acid reflux, gastroesophageal reflux disease and ulcers — but using them long-term can come with digestive downsides. Your stomach's acidic environment acts like a gatekeeper, helping control which bacteria survive and make it to your intestines. When acid is reduced or neutralized, good bacteria may decrease and harmful bacteria can thrive, increasing the risk of infections.[2] PPIs and antacids can also lead to nutrient malabsorption, since stomach acid is essential for absorbing several vital nutrients, including vitamin B12, calcium, magnesium and iron.[3]

When digestive issues flare, finding immediate relief is often a priority. Both prescription and over-the-counter options are effective tools for managing uncomfortable symptoms, but they aren't without consequences. If you're using these medications long-term, talk to your doctor about the risks, and consider lifestyle changes such as dietary adjustments to manage reflux symptoms naturally. For example, cutting back on caffeine, avoiding fatty, fried or spicy foods, and maintaining a healthy weight have all shown benefits when it comes to minimizing digestive disorders.

There are steps you can take to support your gut health before, during and after treatment.

Antibiotics: The Double-Edged Sword

Antibiotics are among the most well-known medications to impact the microbiome. Their job is to kill harmful bacteria that cause infections, but often they don't discriminate. Along with bad bacteria, they can also wipe out beneficial microbes that help maintain a balanced gut environment. This can lead to short-term side effects such as diarrhea or yeast infections and, in some cases, allow harmful bacteria like Clostridioides difficile to take over, leading to painful cramps and diarrhea. Repeated or long-term antibiotic use can also reduce microbial diversity, which has been linked to chronic digestive problems, asthma and obesity.

Research on how quickly antibiotics affect the microbiome and how permanent the effects are varies. A 2017 study stated that even a short course of antibiotics may disrupt the gut microbiome for up to one year or more after the course is completed.[4] However, a similar study conducted in 2020 concluded that for many people, microbial diversity recovered after six months, noting that patient age was a contributing factor. Younger patients experienced longer-lasting effects, and antibiotics taken during the first 18 months of life appeared to cause the most lengthy and significant gut disruption.[5]

In addition, the effects of antibiotics on gut health may depend on:

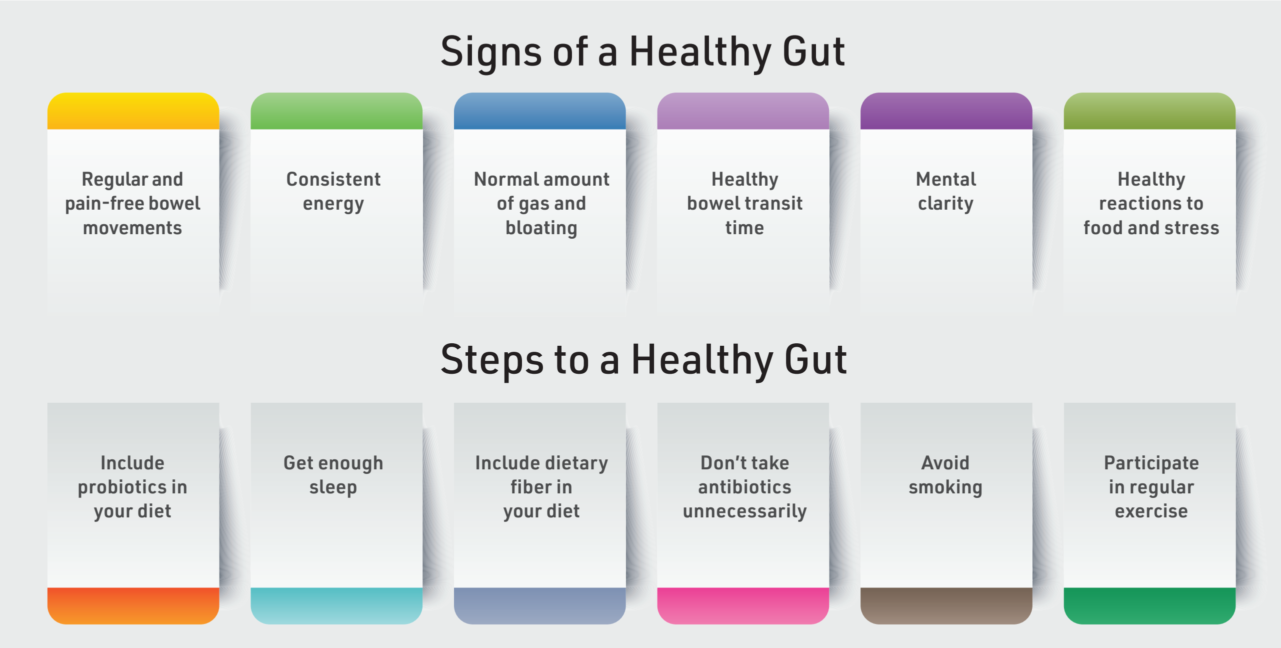
- The type of antibiotic
- Length of antibiotic course
- How many previous courses a person has had
- A person's gut health before he or she began taking the antibiotics

Antibiotics may also adversely affect digestion.[5] Observational studies suggest a connection between antibiotic use in conditions such as gastrointestinal infections, inflammatory bowel disease and even colorectal cancer.

While repeated antibiotic treatment is sometimes needed to fight chronic conditions, to minimize disruption, talk with your doctor about taking probiotics during or after your course to help restore balance. A 2022 study[6] notes that certain types of probiotics may help stabilize the microbiome during treatment or prevent harmful microbes from taking over.

Gut Health and Blood Sugar

Metformin is a drug mainly used to control high blood sugar in people with type 2 diabetes. The drug helps lower blood sugar levels, preventing complications related to diabetes such as kidney damage and vision issues. Studies suggested that metformin alters the composition of the gut microbiota, which in turn may contribute to its glucose-lowering effects. A recent study analyzed the gut microbiota of 25 diabetes patients who received a daily



Adapted from: Everly Well. 7 Signs of a Healthy Gut + Tips To Improve Digestive Health. Accessed at www.everlywell.com/blog/food-allergy/signs-of-healthy-gut.

dose of metformin for the first time. After three months of treatment, the variety and abundance of bacterial species in the gut microbiota decreased, with a reduction in the Firmicutes to Bacteroidetes ratio. Metformin treatment was linked to an increase in Escherichia-Shigella bacteria and a decrease in Romboutsia and Pseudomonas.[7] The findings suggest that metformin regulates glucose metabolism by altering specific gut bacteria and fostering a more efficient response to glucose metabolism.

"Current thinking has been that the metformin works because it improves insulin sensitivity in the liver," said Caroline Apovian, MD, professor of medicine and pediatrics at Boston University School of Medicine and director of nutrition and weight management at Boston Medical Center. "However, these findings, as well as results from recent studies, suggest that the gut may have an active role in glucose metabolism. It could mean that metformin not only helps people with diabetes but could help people with prediabetes and maybe even people without diabetes because you are improving the gut microbiome."[8]

The Laxative Dilemma

Constipation, characterized by infrequent or difficult bowel movements, can stem from various factors, including dietary habits, lifestyle choices and underlying medical conditions. A lack of dietary fiber, insufficient fluid intake and physical inactivity are all common culprits, as well as certain medications, stress and changes in routine. For relief, many of us turn to over-the-counter laxatives or stool softeners. But could these medications cause more harm than good?

Recent studies have highlighted the negative ways laxatives affect the microbiome. One study examined the way polyethylene glycol (a component of many over-the-counter laxatives such as MiraLAX) affected the microbiota of mice. Researchers at the Stanford University School of Medicine in California studied the long-term effects of this medication on the composition of the microbiome. Study results showed that it allowed certain microbes to flourish but hampered the growth of other common microbes essential to good health. After the study, the mice were found to have less diverse gut bacteria overall. The laxatives also influenced the immune system, causing a thinning of the mucus that protects the gut lining. In addition, the immune response to the microbes persisted long after the laxative recovery period.[9]

Similar results have also been found in humans. One study that examined changes in the microbiota of patients following a pre-colonoscopy enema found:[10]

- Changes in the microbiome persisted for a month after the enema, while dose and duration determined the severity of these changes.
- Lactobacilli bacteria was decreased, which could affect immune function and increase the risk of chronic diseases such as diabetes, metabolic syndrome and obesity.

- The numbers of harmful bacteria such as enterobacteria and streptococcus were significantly higher than normal as long as a month after the enema.

All of us experience bouts of occasional constipation. While frustrating and uncomfortable, often upping your fiber and fluid intake for a few days can get you back to having consistent bowel movements. Individuals should consume plenty of leafy greens, dried fruit, whole grains and oatmeal, and drink ample amounts of water to get things moving again.

For chronic constipation, discuss recommended dietary or lifestyle adjustments with your doctor, and consider consulting with a dietitian who can help you create a more fiber-rich, long-term eating plan.

Supporting Your Microbiome While Taking Your Medication

Whether you suffer from occasional infections or live with a chronic condition that is managed by microbiome-altering medications, there are steps you can take to support your gut health before, during and after treatment. In addition to asking your doctor about the potential benefits of probiotic supplements, consider the following lifestyle changes:[11]

Stay hydrated. Water is critical for healthy digestion. It helps your body absorb and transport nutrients, helps keep your core body temperature steady, aids in the production of mucus to protect your digestive tract, and can prevent constipation (so you can avoid the need for laxatives). A common adage is that if you feel thirsty, you are already dehydrated, so drink up!

Keep stress under control. Increased stress often manifests itself in digestive discomfort. Stress causes hormones such as adrenaline and cortisol to spike, leading to symptoms such as diarrhea, constipation, stomach pain and heartburn, all of which can have you heading for the medicine cabinet. While we can't avoid stressful situations entirely, it's possible to learn to manage stress through techniques like deep breathing exercises, mindfulness practices such as meditation or yoga, and even journaling to process emotions.

Prioritize sleep. According to research[11] published in *Frontiers in Microbiology*, certain bacteria in your gut may impact the quantity and quality of your sleep. Most people should aim to get seven to nine hours of sleep a night. If you're consistently struggling to hit that goal, try improving your sleep hygiene, including setting a regular bedtime and minimizing your exposure to the blue light from electronics as bedtime draws near.

Get moving. We all know we should exercise regularly for overall health. Now, a systematic review published in *Nutrients*[12] reported that participating in 150 to 270 minutes of moderate- to high-intensity exercise per week for at least six weeks also has a positive effect on your gut microbiota, particularly if you combine aerobic exercise with resistance training. Studies also show that people who are sedentary have different gut microbiota characteristics than active people, which means you might be able to improve your gut health through exercise even if you're not currently active.

Knowledge Is Power

A medication-free lifestyle might be ideal when it comes to maintaining balanced gut health, but for most of us (especially those living with chronic illness), it's simply not realistic. The good news is, when the medications you rely on for relief from both small and significant health issues lead to gut-bacteria imbalances, knowledge really can be powerful. With the right information and support, you and your doctor can take proactive steps to protect your microbiome. By partnering with your healthcare provider, making mindful medication choices and nurturing your gut through healthy habits, you can maintain a strong and balanced gut — no matter your treatment plan.

References

1. Cohut, M. Common Drugs May Alter Gut Bacteria and Increase Health Risks. Medical News Today, Oct. 23, 2019. Accessed at www.medicalnewstoday.com/articles/326766.
2. Imhann, F, Bonder, MJ, Vila, AV, et al. Proton Pump Inhibitors Affect the Gut Microbiome. *Gut,* 2016;65:740-748. Accessed at gut.bmj.com/content/65/5/740.
3. Mumtaz, H, Ghafoor, B, Saghir, H, et al. Association of Vitamin B12 Deficiency with Long-Term PPIs Use: A Cohort Study. *Annals of Medicine and Surgery (London)*, 2022 Sep 26;82:10476. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC9577826.
4. McDonald, LC. Effects of Short- and Long-Course Antibiotics on the Lower Intestinal Microbiome as They Relate to Traveler's Diarrhea. *Journal of Travel Medicine*, 2017 Apr 1;24(Suppl 1):S35–S38. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC5728355.
5. Schwartz, DJ, Langdon, AE, and Dantas, G. Understanding the Impact of Antibiotic Perturbation on the Human Microbiome. *Genome Medicine*, Volume 12, Article number: 82 (2020). Accessed at genomemedicine.biomedcentral.com/articles/10.1186/s13073-020-00782-x.
6. Patangia, DV, Ryan, CA, Dempsey, E, et al. Impact of Antibiotics on the Human Microbiome and Consequences for Host Health. *MicrobiologyOpen*, 2022 Jan 13;11(1):e1260. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC8756738.
7. Gao, Y, Zhao, T, Lv, N, et al. Metformin-Induced Changes of the Gut Microbiota in Patients with Type 2 Diabetes Mellitus: Results from a Prospective Cohort Study. *Endocrine*, Volume 85, pages 1178–1192, (2024). Accessed at link.springer.com/article/10.1007/s12020-024-03828-x.
8. Escobar, JS, and Apovian, C Metformin Alters Microbiota, Improving Insulin Sensitivity. MedCentral, March 7, 2019. Accessed at www.medcentral.com/endocrinology/diabetes/metformin-alters-microbiota-improving-insulin-sensitivity.
9. A Short Course of Laxatives Has Long-Lasting Effects on Microbiome. *Nature*, 558, 488-489 (2018). Accessed at www.nature.com/articles/d41586-018-05480-8.
10. Lam, M, Lam, C, and Lam, G. The Unhealthy Ways Laxatives Affect the Microbiome. DrLam Coaching. Accessed at www.drlamcoaching.com/blog/laxatives-affect-the-microbiome.
11. Wu, J, Zhang, B, Zhou, S, et al. Associations Between Gut Microbiota and Sleep: A Two-Sample, Bidirectional Mendelian Randomization Study. *Frontiers in Microbiology*, 13 Aug 2023 Accessed at www.frontiersin.org/journals/microbiology/articles/10.3389/fmicb.2023.1236847/full.
12. Boytar, AN, Skinner, TL, Wallen, RE, et al. The Effect of Exercise Prescription on the Human Gut Microbiota and Comparison Between Clinical and Apparently Healthy Populations: A Systematic Review. *Nutrients*, 2023 Mar 22;15(6):1534. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC10054511.

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

Diagnosing and Treating IPEX Syndrome

Outcomes are improving for this rare autoimmune disease, but without an early diagnosis, it can lead to severe complications and even death.

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

IPEX SYNDROME, short for Immune Dysregulation Polyendocrinology, Enteropathy, X-linked syndrome, was first identified in 1982. It is a rare, potentially life-threatening, autoimmune disease that primarily affects male infants and young children. It is named for its constellation of symptoms and its X-linked genetic inheritance pattern. IPEX has played an important role in helping scientists understand how the immune system is supposed to regulate itself. While rare, early recognition of IPEX can be lifesaving, making awareness among patients and healthcare providers crucial.

What Is IPEX Syndrome?

IPEX syndrome is a genetic autoimmune disease in which the immune system, which normally protects the body from infections, mistakenly attacks its own tissues. This immune dysregulation results in widespread inflammation and damage, particularly affecting the digestive system, skin and endocrine organs (such as the pancreas and thyroid). Most children with IPEX begin showing symptoms in the first few months of life. It is characterized by a classic triad of symptoms:[1]

- Digestive issues: Severe, chronic diarrhea, poor weight gain and failure to thrive due to inflammation of the digestive tract
- Hormonal problems: Early onset type 1 diabetes mellitus, thyroiditis and other hormonal imbalances
- Skin conditions: Eczema or other persistent inflammatory skin rashes related to immune system overactivity or dysregulation

Additional features may include autoimmune blood disorders or inflammation in the liver or kidney. The severity and combination of symptoms can vary, but the disease course is typically aggressive without appropriate treatment.

What Causes IPEX Syndrome?

IPEX is caused by mutations in the FOXP3 gene, located on the X chromosome. This gene is essential for the development and function of regulatory T cells, which play a key role in maintaining immune tolerance by preventing the immune system from attacking the body's own cells. Without functional FOXP3, regulatory T cells cannot suppress inappropriate immune responses, leading to the hallmark autoimmunity manifestations of IPEX.[2]

Because the gene resides on the X chromosome, the condition almost exclusively affects males. Female carriers can exhibit milder symptoms due to patterns of X-chromosome inactivation, but this is uncommon.

How Is IPEX Syndrome Diagnosed?

Early signs often mimic more common pediatric conditions, such as atopic dermatitis (eczema), food allergy or infections, making early diagnosis difficult. Diagnosing IPEX requires a multidisciplinary approach. A collaborative effort between pediatricians, immunologists, endocrinologists, gastroenterologists, dermatologists and genetic counselors is often needed to piece together the diverse symptoms and guide diagnostic testing. The diagnosis requires a combination of clinical suspicion, laboratory evaluation and genetic testing:

- Clinical evaluation: Infants presenting with early-onset type 1 diabetes mellitus, chronic diarrhea or severe eczema should raise concern for IPEX. A family history of similar symptoms or unexplained infant deaths in male relatives may also be a clue.

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INDICATIONS AND USAGE

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

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

IMPORTANT SAFETY INFORMATION

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

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

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

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

79%	68%	32%
At least minimal improvement vs 44% placebo (primary endpoint)	**At least moderate improvement** vs 23% placebo (secondary endpoint)	**Major improvement** vs 8% placebo (secondary endpoint)

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

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

Most common drug-related side effects

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

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

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

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

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

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

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

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

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

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

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

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

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CONSUMER BRIEF SUMMARY

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

What is OCTAGAM 10%?

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

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

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

WARNING: THROMBOSIS, RENAL DYSFUNCTION, AND ACUTE RENAL FAILURE

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

Who should NOT use OCTAGAM 10%?

Tell your HCP if you:

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

What should I know before receiving OCTAGAM 10%?

OCTAGAM 10% can cause the following:

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

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

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

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

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

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

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

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

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

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October 2023

- Laboratory testing: Blood tests often reveal elevated immunoglobulin E (IgE), eosinophils and various autoantibodies. Some patients may have signs of multiple organ involvement, including liver or kidney inflammation.
- Protein function: Laboratory testing can also include analysis of the FOXP3 protein expression or the function of regulatory T cells. This can help assess whether regulatory T cells are present and functioning properly.
- Genetic testing: Definitive diagnosis is made by identifying mutations in the FOXP3 gene through genetic sequencing with targeted panels for primary immune deficiency or whole exome sequencing.[1]

Early diagnosis is critical, since untreated IPEX can lead to severe complications or death due to uncontrolled autoimmune damage.

How Is IPEX Syndrome Treated?

Managing IPEX requires a multidisciplinary approach, often involving pediatricians, immunologists, endocrinologists, gastroenterologists and dietitians. Treatment strategies include:

- Immunosuppressive therapies: Medications that suppress the immune system, such as corticosteroids, calcineurin inhibitors (tacrolimus) and mTOR inhibitors (sirolimus), are often used to reduce inflammation and prevent damage. While they help manage symptoms, they are not curative and have side effects such as increased infection risk.
- Hormone replacement therapy: Lifelong insulin for diabetes or other hormone therapies for thyroid or adrenal dysfunction is needed.
- Nutritional support: Digestive issues can lead to severe nutrient malabsorption. A specialized diet, elemental formulas and, in some cases, feeding tubes or intravenous nutrition may be needed to maintain adequate nutrition.
- Hematopoietic stem cell transplantation: A bone marrow or stem cell transplant is currently the only curative treatment. This procedure replaces the patient's defective immune system with healthy donor stem cells. It can restore a functional immune system if performed early enough. Outcomes are significantly better when the transplant occurs before irreversible organ damage. While the procedure carries significant risks, including graft-versus-host disease and infection, outcomes are improving with advancements in donor matching and supportive care.

IPEX Syndrome Research

Given the rarity of IPEX, research has primarily focused on understanding the molecular mechanisms of FOXP3 and regulatory T cell biology. Research on IPEX has significantly shaped our understanding of how regulatory T cells prevent autoimmune diseases.

- Gene therapy: Investigational efforts are underway to correct FOXP3 mutation using gene editing tools such as CRISPR-Cas9. These efforts aim to restore normal regulatory T cell function and immune tolerance.
- Improved transplant techniques: Advances in transplant medicine, including using milder pre-transplant treatments and better donor matching, are helping to make the procedure safer and more accessible.[3]
- Targeted therapies: New biologic agents that more precisely target immune pathways involved in autoimmunity are in development. These therapies could offer improved control of symptoms with fewer side effects compared to traditional immunosuppressants.[4]

Living with IPEX Syndrome

For families affected by IPEX syndrome, the journey is often challenging. Coordinating care and managing complex medical needs can be overwhelming, often requiring significant emotional and logistical support. However, with timely diagnosis, expert care and ongoing research, many children with IPEX are living longer, healthier lives.

Hope for the Future

IPEX syndrome is a rare, but profoundly impactful autoimmune disease. Thanks to advances in genetic testing and treatments such as stem cell transplant, outcomes are improving. Increased awareness and early diagnosis remain essential for optimizing patient care. As research continues to evolve, there is hope for even more effective and targeted therapies in the future.

References

1. Jamee, M, Zaki-Dizaji, M, Lo, B, et al. Clinical, Immunological, and Genetic Features in Patients with Immune Dysregulation, Polyendocrinopathy, Enteropathy, X-Linked (IPEX) and IPEX-Like Syndrome. *The Journal of Allergy and Clinical Immunology: In Practice*, 2020;8(8):2747–2760.e7. Accessed at pubmed.ncbi.nlm.nih.gov/32428713.
2. Bacchetta, R, Passerini, L, Gambineri, E, et al. Defective Regulatory and Effector T Cell Functions in Patients with FOXP3 Mutations. *Journal of Clinical Investigation*, 2018;127(5):1713–1723. Accessed at pubmed.ncbi.nlm.nih.gov/16741580.
3. Barzaghi, F, Amaya, Hernandez, LC, Neven, B, et al. Long-Term Follow-Up of IPEX Syndrome Patients After Different Therapeutic Strategies: An International Multicenter Retrospective Study. *Journal of Allergy and Clinical Immunology*, 2018;141(3):1036–1049.e5. Accessed at pubmed.ncbi.nlm.nih.gov/29241729.
4. Voarino, M, Consonni, F, and Gambineri, E. Expanding the Spectrum of IPEX: From New Clinical Findings to Novel Treatments. *Current Opinion in Allergy and Clinical Immunology*, 2024;24(6):457–463. Accessed at pubmed.ncbi.nlm.nih.gov/39475830.

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Profile: Heather Holcomb

By Trudie Mitschang

HEATHER HOLCOMB and her husband Jesse suspected something was wrong when daughter Rilyn seemed to be "healthy" only while on antibiotics. After a decade-long journey, the Wisconsin couple learned Rilyn was suffering from activated PI3K delta syndrome (APDS), a rare primary immunodeficiency (PI) that affects approximately one to two people per million. APDS occurs when there are variations to the PIK3CD or PIK3R1 genes, and symptoms include frequent and severe infections of the ears, sinuses and upper and lower respiratory tracts that usually begin in infancy. People with APDS are susceptible to swollen lymph nodes or an enlarged spleen (splenomegaly), as well as autoimmunity and inflammatory symptoms. They may also be at higher risk for cancers such as lymphoma.

Trudie: When did you begin to worry about your daughter's health?

Heather: I suspected something was really wrong when she was around 1 or 2 years old, because she would be OK only when taking antibiotics. Then within a few days of being off of them, she would get sick again with ear infections, coughing and gunky eyes. It took nearly 10 years and dozens of doctors for us to discover the underlying issue.

Trudie: Describe that journey and how it impacted your family.

Heather: It was awful. I had doctors tell me it was my fault! One allergy doctor said she was congested and sick because I drank a lot of dairy products while I breastfed her. I had another doctor tell me, "You can keep bringing her in, but I don't know what you expect me to do." This was when I was bringing her in every week for five weeks in a row when she was less than 1 year old because she would cough and stop breathing at night. Looking back, she had surgeries that were probably unnecessary, but at the time, she wasn't diagnosed so we were doing what we thought was best. Twice, doctors said she probably had cancer. Waiting for the answer as to whether a biopsy is benign or not is excruciating. It was hard for me to work a normal job because I was gone at least once a week, for years, because she was so sick. Knowing something major is wrong with your child but not having a name for what is wrong is a worry that's hard to describe. Rilyn has seen literally hundreds of medical professionals. At one point, she had 14 regular doctors with different specialties (one for lungs, one for ears, one for GI, etc.).

Trudie: How did you navigate issues with insurance?

Heather: Some days, I had to take an entire day off just to coordinate care and deal with insurance denials. I fought with one insurance company because it would deny tests when it didn't even know what the tests were for. Once it denied what it coded as a blood test, but it wasn't a blood test, it was a nasal nitric oxide test that uses exhaled air, not blood. I took days off work to attend in-person appeals to fight ridiculous denials like that one. I won every time.

Trudie: What was your daughter's childhood like before diagnosis?

Heather: More than 100 ear infections by age 2. She's had nine sets of ear tubes, bronchoscopies with lung lavages (washes), four sinus surgeries, plus upper endoscopies and colonoscopies. At one point, a doctor wanted to remove part of her lung. The surgeon refused (thank goodness) because it was too risky. She's always been a really likeable person and makes friends easily, but she has mentioned that in elementary school, kids would shy away from her because of her constant runny nose.

Trudie: What was the emotional toll on you as a mother?

Heather: Gosh, it's been incredibly hard, but I hesitate to complain. I don't want her reading anything about how hard it's been on me. The last thing I want is for her to worry about how it has affected me.

Trudie: Tell us about Rilyn's journey to diagnosis.

Heather: I never quit taking her to doctors. I just kept making appointments because I knew something was wrong. She had her blood drawn for IgG levels multiple times. They drew it again at age 8 or 9 years, and her IgG levels were low. It had been normal every other blood draw. Her initial diagnosis (that she held for four years) was primary ciliary dyskinesia (PCD), and her treatment plan followed what you do for PCD: vest therapy, nebulizers, surgeries and multiple medical procedures. Then my health insurance plan changed, and we were forced to start over instead of continuing with the facility where her PCD was being treated. Initially, I was furious, but it actually ended up being the pathway to diagnosis.

Trudie: How did you navigate that change with insurance?

Heather: When we started over, we went back to the allergy/immunology department to have Rilyn's bloodwork updated. When the results came back, her IgG levels were low. Next, we went to a PCD clinic in Minnesota to get a confirmation that it was in fact PCD, and that doctor said he suspected she had a PI. We told this to her allergist/immunologist, so they ordered another blood test that was to be sent to California to check for possible PIs. Her results came back with a mutated PIK3CD gene and a diagnosis of APDS.

Trudie: What was your daughter's initial treatment plan?

Heather: After her diagnosis, we were sent to the University of Wisconsin Madison Hospital (UW Madison) immunology department for evaluation and treatment, and we were eventually referred to the National Institutes of Health (NIH) in Bethesda, Md., where we have gone one to two times per year for the past five years. UW Madison prescribed her immune globulin (IG) replacement therapy, and NIH prescribed a daily antibiotic and sirolimus. In 2023, she was enrolled in a clinical trial at the University of California, Los Angeles (UCLA) for the drug leniolisib (marketed as Joenja), so she stopped taking sirolimus and took leniolisib instead. She finished that trial in May 2024 and has been treated with Joenja ever since. She continues on the weekly subcutaneous IG (SCIG) therapy and a daily antibiotic. She did try intravenous IG but ended up with aseptic meningitis, which led to a hospitalization for brain and spinal cord swelling. Since then, she has to be treated with SCIG.

Trudie: What did it feel like to finally have a diagnosis?

Heather: As I'm thinking about that day, I'm crying. My kids being born were the best two days of my life. Getting Rilyn's diagnosis was the third best day of my life. I felt like I was literally floating, and I wanted to call everyone on my phone contact list to tell the good news.

Trudie: How is Rilyn's health today?

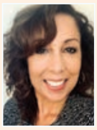
Heather: Great! Her eardrums still rupture about every year, and when she gets a respiratory infection, it can knock her down, but she hasn't needed to be hospitalized. Her lungs are improving, and her enlarged spleen is shrinking. There are fewer doctor appointments. It's a calm feeling knowing what "it" is. She used to miss lots of school, and now she misses only about 10 days a year.

Trudie: What has this experience taught you about yourself?

Heather: I learned that I definitely don't give up when things get hard, and I'm not afraid to respectfully question authority figures.

Trudie: What advice do you have for other parents of children living with chronic illness?

Heather: Your child isn't his or her disease. My daughter is an ice skater, great friend, community volunteer, excellent student and a loving person. If your child has a chronic illness but no diagnosis, you aren't crazy. You aren't making it up. It's real, and I am so incredibly sorry that there isn't an answer yet. Keep fighting, but don't do it alone. Find a support system that can help keep you standing when you feel like giving up. But also, it's OK to take a break and fall down sometimes. Take care of yourself, and give yourself grace when you don't feel like working on this 24/7. It's OK to fall down and take a break, but then rely on your support system, get back up and keep fighting for answers. IG



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When Life Gets Exhausting

By Whitney L. Ward

LIFE CAN get exhausting sometimes. It's OK to admit that. A couple of weeks ago, I stood in front of my mom with tears in my eyes. "It's just so much sometimes," I whispered. At the time, I was juggling sickness, grad school, paperwork for the Social Security Administration and Job and Family Services, doctor appointments and work obligations — not to mention all the medication and treatments I take and manage daily to keep me well.

Then there were all the explanations about why I was late, which ranged from GI issues, morning stiffness and feeling sluggish, as well as trying to help people understand why I can't do some of the things they can do and explaining that I must protect my body and organs from further damage my disease has already caused.

I was being pulled in so many directions at once, and I became weary of it all. I either had to come to terms with the fact that I needed to create better balance or my immune system would crash. Here's what I had to do about the different areas of my life that felt overwhelming:

Doctors. I have six specialists at the National Institutes of Health, four specialists at Nationwide Children's Hospital and five specialists at Ohio State University. With 15 specialists, that's 15 different perspectives to juggle. Each doctor studies a different type of medicine, so when one doctor suggests a treatment plan, another doctor may be against it because of how the medication could possibly affect my body. So, who do I listen to when that happens?

Me! Doctors may know how to treat my illness, but I have the experience of living with it every day. So, I need to listen to what my body is telling me. What is giving me the most pain? What ailment disrupts my life the most? I know my body best, and I should have 100 percent autonomy on my course of treatment.

Explanations. For most of us with compromised immune systems, taking medications and treatments is a part of our routine. We often do these things for our health without thinking, and this routine gives us a quality of life. But then the flare hits, and people begin looking for explanations, asking: "Why is your sinus infection different from my allergies? Why do you have to rush to the bathroom sometimes? Why is it hard for you to stand for a length of time, but not walk? Why do you have to pace your energy while others are still going strong?" We can feel like we are being interrogated, and having to explain our limitations to people who don't understand chronic illness can feel like we're wearing an invisible 100-pound weight.

But here's the thing to remember: When we explain our situation, we aren't giving a defense; we are telling someone our story and the reality of our lives. Facts aren't up for debate, and if someone questions the truth of what we live with, then that person is simply ignorant.

Balancing act. Work, kids' activities, spending time with family, running a household — all these things are time-consuming and tiring. But add a chronic illness you have to manage? It can feel like you have three full-time jobs. When you have to take a step back to protect your health, it can feel like people are thinking, "Just another thing wrong with them."

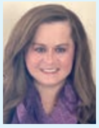
Here's one thing to remember: Everyone needs help. Everyone has limitations. Our limitations are not greater than others' limitations; they are just more visible.

We might be late to an event or meeting because of a flare, but we were there: Celebrate that.

We might have to say no to some things so we can have energy for other things: Celebrate that.

We might have to talk about our condition with someone who doesn't understand our limitations, but we planted seeds of kindness, compassion and perspective: Celebrate that.

We must: Know our worth. Remember our truth. Protect our peace. When life becomes hard — and it will — remember good will eventually replace it.



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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Finding Your Perfect College Fit

By Michelle Searle

CHOOSING THE right college is a big decision! It's exciting, a little scary and, let's be real, very overwhelming. Being part of the immune globulin (IG) community, there are some extra things to consider. Balancing classes, friends and healthcare isn't easy, but with some planning, you can find a school that fits your needs and lets you live your best life.

Tour campuses and ask questions. Campus tours are your chance to see what life is like at a particular college. Here are a few questions you can ask:

- How would you describe this college's culture?
- What differentiates this college from others?
- What accommodations are offered for students with chronic illnesses?
- Is the campus health center familiar with managing complex medical needs?
- What medical facilities are nearby?
- How does the college's student health insurance plan work for out-of-state or international students?

Keep your healthcare close. If you're treated with IG therapy or have regular appointments, you'll want to choose a college with good hospitals and doctors nearby. You will need to consider whether you will continue seeing your doctors back home or if you want to find new ones near your college. Before committing to a school, do some digging. Do the nearby infusion centers and hospitals take your insurance? Is there a doctor who understands your condition?

Check your insurance. If you're moving out of state (or even out of the country), call your insurance company and make sure you will be covered in your new location. If your college offers its own health plan, compare it to your current one to see which works better for you. You won't want to think about insurance while adjusting to a new schedule, settling into your dorm and trying to make new friends.

What's the deal with campus health? Every school's health services are different, so you have to ask the right questions. Does the campus health center know how to handle chronic illnesses? Are they open to working with local doctors if you need them? How will it work to have your medicine delivered to your dorm? Knowing they've got your back makes a huge difference.

Dorms, food and all the details. Living on campus is a whole vibe, but you want to make sure it's one you're comfortable with. Look into dorm options. Can you get a private bedroom or bathroom? Is there space for your medical equipment? Talk to the dining services team to make sure it can handle any dietary restrictions you've got.

Be flexible with academics. Life happens, especially when you're managing a chronic illness. Check out the schools' disability resource center, either online or in-person, to see what impressions it gives you. If needed, look for a college that offers online or hybrid classes and policies that allow you to reschedule exams or take extra time on assignments if you're not feeling well.

A personal story. When I went away to college, I moved about a two-hour drive from home. I loved being away at school while still close enough to visit home when I wanted. I decided to stick with my established immunologist instead of finding a new one, which worked out since I could plan appointments during visits home. When I got sick, my college's health services center was my go-to for quick care. Before classes started, I registered with the adaptive services office for accommodations, which was a huge help. The office gave me extra time to finish assignments whenever I was sick or dealing with medication side effects.

Yes, your health is important, but don't let it stop you from dreaming big. Finding that balance between chasing your goals and staying healthy is key, so have an open mind when considering your college options. Picking the right college is about more than just academics. For those of us in the IG community, it's about finding a place where we can crush it in the classroom, make friends and take care of ourselves. By thinking about things such as healthcare, insurance and campus resources, you'll be set up for success. Don't let your condition decide your future. You're in charge of that. And remember, you're not alone in this. With the right prep and support, college can be an amazing adventure. 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.

Back to School Tips for PI Kids

By Jessica Leigh Johnson

AS STUDENTS prepare to head back to school, they're bound to experience a mix of emotions. They may be excited to see friends again and get back to fall sports, while also being nervous to tackle a difficult class or move up to a new grade or even a new school. Every school year comes with its own rewards and challenges, but for children with primary immunodeficiency (PI), there is another concern: Will their condition keep them from being present in school and getting an education?

To help prepare kids with immune deficiencies head back to school with confidence and ease the burden of worry about how their health might affect their education, parents can do several things, including focusing on healthy habits, preventing infections and ensuring their children are well-supported at school.[1]

Adopt Healthy Habits

At the start of every school year, it's common for kids to come down with colds. Not only are they in close quarters with many others for the first time in months, but there are also several viruses that circulate in the fall, including enteroviruses and influenza. Colds, stomach bugs, strep throat, impetigo and pink eye are all common ailments that can affect school-age kids.[2] To cut down on the number of absences due to illness, kids with PI can strive to adopt healthy habits to support their immune systems:

1) Be sure to get enough sleep. Setting the alarm for 6 a.m. on that first day back to school can be a shock to the system, and kids may be tired after the summer break. Lack of sleep is known to weaken the immune system and can make kids more susceptible to illness, especially those with PI. But how much sleep do children need? According to the American Academy of Pediatrics, preschoolers need 10 to 13 hours of sleep daily, including naps. Children ages 6 to 12 should get nine to 12 hours of sleep, and teens need eight to 10 hours of sleep.[2]

If kids aren't meeting these sleep requirements, their parents can help by making their bedtime earlier, at least at the beginning of the school year. Also, they can make sure their children's bedrooms are cool and dark, and that screen time is cut off well before bedtime. For younger children, having a regular bedtime routine, including a bath, story time or listening to quiet music, might help them relax and fall asleep easier.[2]

2) Reduce stress. Stress can affect children's overall health and well-being. Not only can chronic stress cause anxiety and depression, but over time, it can wear down the immune system. To help children reduce back-to-school stress, parents should check in with them and ask if there's anything they're concerned about when it comes to going back to school. Parents should also keep an eye out for signs of anxiety, including changes in sleep patterns, eating or behavior.[2] If stress or anxiety seem to be a problem, parents can seek help and support from a mental health professional.

Finally, for kids to be able to relax and unwind after a long day at school, they need time to play. Parents can let their children choose after-school activities, but they should encourage physical activity as much as possible.

3) Offer healthy food choices. While eating a healthy diet is important for everyone, it's even more important for kids with PI, especially when their bodies are still growing and they're busy with back-to-school activities. Offering meal choices that include foods from all five food groups helps kids receive a good mix of vitamins, minerals and nutrients. Also, avoiding added sugar and sugary beverages aids in improving overall health by reducing inflammation and cutting down on unhealthy weight gain. Some foods are even known to help boost kids' immune systems. These foods include fruits and vegetables, yogurt for good gut health and whole grains and lean proteins for energy.[2]

4) Reduce the spread of germs. It may sound simple, but regular handwashing is the best way to prevent the spread of germs and keep school children healthy. Both children and adults should wash their hands after sneezing or blowing their nose, using the restroom, touching doorknobs, desks and handrails, and especially before and after eating.[2] Soap and water are best for handwashing, but if they aren't readily available, kids can opt for an alcohol-based hand sanitizer.

Because school is an environment where children are in close proximity to one another, the likelihood of spreading colds and other illnesses is increased. Germs can easily spread through the air from coughs and sneezes, on surfaces or by touching contaminated objects.[2]

And lastly, although it almost goes without saying (especially for families of kids with PI), kids who are sick should stay home from school. Not only will this reduce the spread of germs to other children, but staying home and getting adequate rest will help sick children recover more quickly.

> ***Before the school year begins, parents should inform the school staff — including the teachers, principal and school nurse — about their child's immune deficiency.***

Create a Plan with School Staff

Before the school year begins, parents should inform the school staff — including the teachers, principal and school nurse — about their child's immune deficiency. Many of the school's employees have probably never heard of PI, and a meeting to discuss any specific needs or accommodations the child may require would help to get everyone on the same page, especially when your child is new to the school or when your school has new staff who do not know your child.[1] Annual meetings are helpful for meeting and informing your child's new teacher and reviewing your child's needs with him or her along with the support staff so that everyone understands and agrees to the accommodations. In some cases, a 504 plan may be needed to implement these accommodations. A 504 plan is a document that outlines specific steps the school must take to create an environment where a child with certain limitations or conditions can achieve his or her potential. Some common accommodations that might be made for a child with PI include:[3]

- A bathroom pass as often as the child needs it
- An extra set of books to keep at home in case of missed school days
- No penalty for extended absences
- A copy of missed in-class notes provided by the teacher when the child is absent
- Flexible seating arrangements to allow distance from sick classmates
- Prompt notification of disease outbreaks
- Unlimited access to the school nurse

The Immune Deficiency Foundation has created a revised guide for families of students with PI, which can be accessed at their website at www.primaryimmune.org. This guide is an excellent resource to provide to school employees such as teachers, principals and school nurses when a child with PI will be attending their school. One key matter the guide emphasizes is the responsibility school staff have in watching out for infectious diseases outbreaks (such as influenza, COVID-19, whooping cough, measles and strep) and notifying the parents of kids who have PI right away. This guide will also remind school officials to enforce best practices such as routine handwashing and using hand sanitizer, especially before eating, after visiting the restroom and after being outdoors.[3]

Empower Kids to Advocate for Themselves

The best thing parents can do for their school-age kids is to empower them to be their own advocate when it comes to both their health and their education. From early on, parents should teach their children about their health condition, include them in their 504 planning, stress the importance of good hygiene practices like handwashing, and support them if they choose to tell others about their PI. The sooner parents get involved with their children's education, the better the experience will be for them.[3] IG

References

1. Cottier, C. Back to School Tips for Kids with Primary Immunodeficiencies. CSL Behring, Sept. 6, 2022. Accessed at www.csl.com/we-are-csl/vita-original-stories/2022/back-to-school-tips-for-kids-with-primary-immunodeficiencies.
2. Preventing Back to School Sickness. Children's Health. Accessed at www.childrens.com/health-wellness/preventing-back-to-school-sickness.
3. Immune Deficiency Foundation. Educate Schools on Primary Immunodeficiency to Better Support Your Child, Aug. 27, 2022. Accessed at www.primaryimmune.org/resources/news-articles/educate-schools-primary-immunodeficiency-better-support-your-child.

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.

Sleep Aids

By Rachel Maier, MS

IS THERE anything better than a good night's sleep? You just can't beat the feeling of waking up rested and ready for a new day. But only 42 percent of U.S. adults say they actually get as much sleep as they need, and 57 percent say they would feel better if they got more sleep. Adults should get between seven to nine hours every night, but only 27 percent of U.S. adults get that much.[1]

Sleep Hygiene

Sometimes all you need to get a better night's sleep is to improve your sleep hygiene. (Sleep hygiene is a set of practices and routines that help you get better sleep.[2]) Consider the following: Do you have a set sleep schedule, follow a nightly routine, avoid electronics and large meals before bed and have a calm, comfortable bedroom? How can you reasonably adjust your home and habits to support your need for good rest? Small adjustments may be all you need for a better night's sleep.

Natural Sleep Support

However, some of us need a little more help. Sipping on a calming nighttime beverage might be an easy, enjoyable way to ready your body for sleep. For example, "bedtime blend" herbal teas contain ingredients such as chamomile to help you relax, valerian root with a natural sedative effect and passionflower to ease anxious minds. Warm milk contains tryptophan, which helps produce serotonin and melatonin, both of which help your body feel ready for sleep. Unsweetened tart cherry juice is a source of naturally occurring tryptophan and melatonin. (Melatonin is a hormone your body naturally makes that plays a role in the body's circadian rhythm and sleep-wake cycle.[3])

Another strategy is taking supplements. In fact, taking supplements before bed is increasingly popular. Bedtime gummies are all the rage, many of which contain melatonin. Melatonin supplements are generally considered safe, but there are certain populations for whom it is not recommended (for example, people with autoimmune disease, as it may interfere with immunosuppressive therapy, or people with diabetes, as it may affect blood sugar levels. Ask your doctor if it's right for you).[4] Alternatives to melatonin include blends of ingredients such as ashwagandha, chamomile, gamma-amniobutyric acid (GABA), glycine, L-theanine, lavendar, magnesium, magnolia bark, passionflower, valerian root and vitamin B6. However, it is important to understand these sleep aids are not regulated by the U.S. Food and Drug Administration (FDA).

Over-the-Counter Sleep Aids

If the natural route doesn't work for you, you may consider an over-the-counter drug-based option. Doxylamine succinate and diphenhydramine are antihistamines that make you feel drowsy, so they are the active ingredient in sleep aids such as Unisom and ZzzQuil, which are regulated by FDA. Before taking them, ask your doctor if these sleep aids are right for you.

Talk to Your Doctor

Adding sleep aids to your nightly routine can help you get more of the sleep you need. However, while the products featured in the shopping guide are generally considered safe, make sure to talk to your doctor before using them, as even natural supplements may interact with your medication(s).

References

1. Fioroni, S, and Foy, D. Americans Sleeping Less, More Stressed. Gallup, April 14, 2024. Accessed at news.gallup.com/poll/642704/americans-sleeping-less-stressed.aspx.
2. Solodar, J. Sleep Hygiene: Simple Practices for Better Rest. Harvard Health Publishing, Jan. 31, 2025. Accessed at www.health.harvard.edu/staying-healthy/sleep-hygiene-simple-practices-for-better-rest.
3. Cleveland Clinic. Melatonin, reviewed July 5, 2022. Accessed at my.clevelandclinic.org/health/articles/23411-melatonin.
4. Mayo Clinic. Melatonin, Aug. 10, 2023. Accessed at www.mayoclinic.org/drugs-supplements-melatonin/art-20363071.

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

Mary Ruth's Extra Strength Liquid Nighttime Multimineral Vitamins

Add this to your sleep routine and support your body with nourishing vitamins and minerals while you rest. This liquid multimineral is high in magnesium, which helps with healthy muscle relaxation, and also contains other essential nutrients your body needs to support less stress and calm, including vitamin C, magnesium citrate, calcium, vitamin D3 and more. No hard-to-swallow pills and no melatonin — perfect for both adults and children. *$42.95; www.maryruthorganics.com/products/lemonade-liquid-nighttime-multimineral-32oz-br-deep-sleep-relaxation-cell-repair*

Get Some Zzz's Herbal Tea

Brew a cup of this caffeine-free herbal blend and breathe a sigh of sweet relief as the bouquet of rooibos, soothing chamomile, passionflower and the mellowing properties of valerian root gently lull you toward blissful rest. It won't interfere with REM sleep, so you won't have to contend with the morning hangover that often results from other sleep aids. Just one cup before bed can help you say goodnight to tossing and turning. *$13; www.republicoftea.com/get-some-zzz-herb-tea-for-rest/p/v00729*

Shopping Guide for Sleep Aids

The Good Patch: Slumber

This wearable wellness patch for bedtime is infused with L-theanine, magnesium and tart cherry extract. Perfect for quick power naps or a much-needed bedtime. Powered by an innovative dermal delivery system, these wellness patches stick right to your skin and provide a steady release of premium ingredients for up to 12 hours. They're safe, work quickly and are easy to use. *$12 for four patches; thegoodpatch.com/products/slumber?srsltid=AfmBOooIq31CcQcArJx5DkPrkQAZpjWhJNec0Bvfg1SYR0sMquKYL6xj*

Natrol Sleep & Restore Melatonin-Free Gummies

Indulge in restorative sleep with these melatonin-free, cherry-flavored gummies designed to help you relax, unwind and enjoy a better night's rest. Each serving delivers 100 mg GABA, 100 mg magnesium and 10 mg vitamin B6 to support sleep and help you feel rejuvenated, along with 25 mg botanical blend of tart cherry, lemon balm and chamomile. These 100 percent drug-free gummies are non-GMO, vegetarian, gelatin-free and free from synthetic dyes and artificial flavors. They provide trusted, non-habit-forming sleep support to help you wake up refreshed and ready to take on the day. *$18.99; www.amazon.com/Natrol-Magnesium-Glycinate-Melatonin-Free-Flavored/dp/B0DS7X3P1L*

Better You Natural Sleep Supplements

A good night's sleep is vital for your health and well-being, but it's not always easy to achieve. With pill-free magnesium supplements designed to help you sleep, you'll be prepared for a peaceful night's rest. This line of topical magnesium supplements blended with soothing lavendar and calming chamomile includes body lotion, body spray and bath flakes so you can personalize your sleep experience. *$14.95; us.betteryou.com/collections/sleep-supplements*

Cheribundi SLEEP

Tart cherry juice with naturally occurring melatonin and blended with L-theanine and valerian root equals deeper, longer, sounder sleep. *$30/12 pack; cheribundi.com/products/sleep-tart-cherry-juice?variant=39738190921798*

Caregiver Compassion & Connection Guide

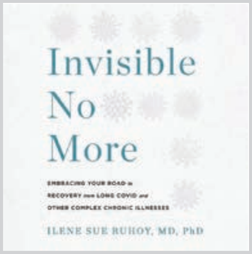
Author: Immune Deficiency Foundation
Publisher: Immune Deficiency Foundation

The *Caregiver Compassion & Connection Guide* is written for parents, partners, friends and those caring for a parent. From medical management to emotional support, this guide offers a starting point for caring for a loved one with primary immunodeficiency (PI), while also taking care of yourself. It includes essential facts about PI, caregiving essentials, advocacy and support, self-care for caregivers, and support and resources. It can be downloaded for free at primaryimmune.org/resources/print-material/caregiver-connection-compassion-guide.

Invisible No More: Embracing Your Road to Recovery from Long Covid and Other Complex Chronic Illnesses

Author: Ilene Sue Ruhoy, MD, PhD
Publisher: St. Martin's Essentials

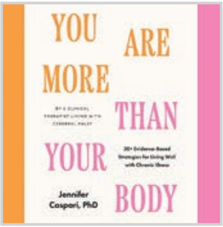
In *Invisible No More*, Dr. Ruhoy aims to empower the long-term patients of chronic and complex diseases, delving into her own harrowing experience as a patient. She details her evolution as a neurologist, toxicologist and integrative physician to work with people across the globe in treating their chronic symptoms and disabling disease, all while amplifying their own voices. This book serves as a practical guide with sections on nutrition, breathing, supplements and more. With a focus on healing and empowerment, it will answer patients' most pressing questions and help them take their health into their own hands.



New and Useful Reading

You Are More Than Your Body: 30+ Evidence-Based Strategies for Living Well with Chronic Illness

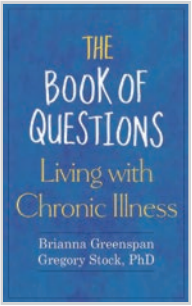
Author: Jennifer Caspari, PhD
Publisher: North Atlantic Books



You Are More Than Your Body weaves together clinical expertise, personal stories and practical, evidence-based tools to help readers with chronic health conditions better cope with pain, fatigue, depression and the emotional vulnerability that comes with living in a world not designed for their bodies. The methods in this book synthesize a wide range of emotional regulation skills and coping techniques drawn from cognitive behavioral therapy, acceptance and commitment therapy and mindfulness practices, all of which Dr. Caspari has successfully used with her own clients. Readers will learn more than 30 practical coping skills.

The Book of Questions: Living with Chronic Illness

Authors: Gregory Stock and Brianna Greenspan
Publisher: Nquire Media



As the newest addition to the Book of Questions series, *The Book of Questions: Living with Chronic Illness* offers readers the opportunity to look within themselves for answers. The book poses questions such as "When have you shown great courage and grit in overcoming something most people take for granted?" and "What stories do you tell yourself about your illness, and what purposes do they serve for you?" — all designed to empower readers to face difficult topics, deepen connections through honest conversations and create their own path of acceptance and fulfillment — whatever their health condition may be.

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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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IG Living Advocate Podcast

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.

Podcasts will cover topics such as the increased demand for IG

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