February-March 2026

IGLiving

IGLiving.com

20th Anniversary Issue

Creating Routines to Support Your Health

How to Live Well with Chronic Immune Conditions

Pharmacy Benefit vs. Medical Benefit?

Treating Autoimmune Cytopenias in PI Patients

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

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

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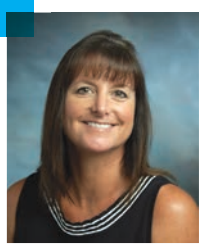
Subscriptions to IG Living are free, and readers may subscribe at IGLiving.com or by calling (800) 843-7477 x1461.

20 Years! Thanks to All: It's Only the Beginning



20 YEARS! Twenty years ago, we started with a simple mission: to inform you about your diseases and treatment options, give you strategies for communicating about your struggles with complicated illnesses, and assist you in advocating for yourself to get the care you need and deserve.

Twenty years later, we've come a long way! Our first issue of *IG Living* was mailed to thousands of individuals with primary immunodeficiencies (PIs) treated with immune globulin (IG) therapy. Today, our readership has grown to more than 35,000 patients and the individuals who care for them. This growth is spurred by the discovery of what we now know are more than 550 PIs, as well as the growing number of individuals with autoimmune, neurological and other conditions that require IG replacement therapy.

Diagnosis and treatment have also progressed. While it still takes about six to 12 years to be diagnosed with a PI, there is now greatly enhanced awareness about these rare diseases affecting our community, which has shortened diagnosis time for many. Also 20 years ago, there were merely a handful of IG products, all of which were intravenously administered. Now, there are more than 17 IG products and the options of subcutaneous administration and home infusion.

Over the years, this magazine has captured patient stories, provided articles to help improve the daily lives of those living with long-term conditions, and highlighted voices that deserve to be heard. We hope these articles have resonated with others experiencing similar hardships and triumphs — stories that helped you to connect with one another and have given you a sense of belonging and a place to find answers.

In this special anniversary issue, we asked for your picks for the articles that have helped you most, which we feature on page 22. We hope these articles will provide a quick reference to the information most important to you. We also list our staff's choice of some of the most inspirational patient profiles over the past 20 years on page 26. You can find these articles and profiles on our website at www.IGLiving.com. Direct links to each of them are provided.

Thank you to our loyal readers and contributors who have made the past 20 years possible — this anniversary belongs to you. Our success has been driven by a community of patients and caregivers who believe in our mission. We're honored that for two decades you've turned our pages, shared your stories and grown with us. Twenty years is only the beginning.

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

Ronale Tucker Rhodes

Ronale Tucker Rhodes, MS

IGLiving

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

A community service from FFF Enterprises, Inc.

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

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- **Free IG Resources:** A collection of powerful tools to simplify and streamline your practice
  - IG Reimbursement Calculators
  - IG Reference Charts
  - IG Living, a magazine dedicated to the IG community

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Scan the QR code and search under Biologics to learn more.

Scan the QR code and go to Resources to learn more.

Protecting Yourself Against Medical Identity Theft

By Abbie Cornett, MBA

EVERY DAY, we hear news about data breaches. Sometimes it's a bank or a store, but increasingly, these breaches involve medical data. For patients living with chronic illness, that can be especially upsetting. Your medical information isn't just about your health; it's about who you are, and it can be worth more to a criminal than your credit card number.

When someone steals your medical records, they're getting much more than your health information; they are getting your full name, date of birth, address, Social Security number, insurance details, medical ID numbers and, sometimes, payment information. That's everything a thief needs to build or sell your identity. Unlike a credit card number that you can cancel quickly, your medical information doesn't change. You can't get a new date of birth or a new medical history. This makes it extremely valuable on the black market. Criminals can use it to obtain prescription drugs, file false insurance claims, open credit lines or apply for government benefits using your identity. According to the Federal Trade Commission (FTC), this type of theft is called medical identity theft — when someone uses your personal information to get medical care, goods or services in your name.[1] The North Carolina Department of Justice adds that this can even lead to false information appearing in your medical records, which can affect your care and your insurance.[2]

Medical identity theft can happen in many ways. A thief might steal your medical insurance card or Medicare number, hack into a doctor's or hospital's database, trick you into giving personal information through fake calls or emails (a type of scam called phishing) or use data from a breached health app or pharmacy account. Sometimes, it's even an insider who works in a clinic or billing office who sells or misuses patient data. For people managing a chronic illness, the risk can be higher. You might have several doctors, pharmacies or labs handling your records, which means more points where data could leak.

If you have a chronic condition, your medical information becomes an integral part of your daily life. You rely on accurate records for ongoing treatment, medications and insurance approvals. If someone uses your identity, your medical record can become mixed with theirs, and that can be dangerous. Wrong information could affect your treatment, delay needed care or cause serious complications. You may also receive unexpected bills or discover that your insurance benefits have been exhausted. The FTC warns that these errors can be difficult to correct because medical records are often scattered across various systems.[1]

You can't stop every data breach, but you can take steps to protect your medical identity and lower your risk: 1) Guard your information. Keep insurance cards, medical bills and records in a safe place. Shred papers that include personal information before throwing them away. 2) Be careful online. Avoid clicking on links or attachments in emails or texts about your health unless you expect them. Use strong passwords and log out of patient portals when finished. 3) Check your medical and insurance statements. Read your explanation of benefits and medical bills closely. If you see charges for visits or prescriptions you didn't receive, contact your provider or insurer right away. 4) Ask questions. If a medical office asks for your full Social Security number, ask if they can use another ID number instead. 5) Reduce what you share. Before entering medical data into an app or website, check its privacy policy. Avoid posting health details on public social media.[3]

If you suspect your medical identity has been stolen, contact your health insurance company or Medicare, review your medical records and report false information to your providers. Check your credit report for medical debt or collections you don't recognize, and report the issue to the FTC at IdentityTheft.gov to create a recovery plan.[4]

Medical identity theft is growing, and as healthcare becomes more digital, patients must take an active role in protecting their information. For those living with chronic illnesses, it's especially important because your health and financial security are closely linked. Think of your medical data as one of your most valuable possessions. Guard it the same way you would your bank account or house keys. IG

References

1. Federal Trade Commission Consumer Advice. What to Know About Medical Identity Theft. Accessed at consumer.ftc.gov/articles/what-know-about-medical-identity-theft.
2. North Carolina Department of Justice. Medical Identity Theft. Accessed at ncdoj.gov/protecting-consumers/protecting-your-identity/medical-identity-theft.
3. Horney, C, and Petrino, G. Preventing Medical Identity Theft in 2025. Security.org. Accessed at www.security.org/identity-theft/medical.
4. Federal Trade Commission. When Information Is Lost or Exposed. Accessed at www.identitytheft.gov/Info-Lost-or-Stolen.

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

What's Your Go-To Tip for Making Infusions More Comfortable?

My Kindle, an iced tea/water, fleece blanket and a salty snack.

Salty snacks, watermelon, electrolyte replacement, stretchy pants/shorts, a good Netflix show and my dog for snuggles!

My Mets blanket, my husband and the world's best nurses at Mount Sinai Hospital's infusion center.

A comfortable recliner, a good book, TV remote, a large glass of water with liquid IV, a hot cup of tea and my Zebra blanket (given to me by a good Zebra friend).

How Do You Break Up Cleaning into Manageable Steps?

I use my commercial cleaning method. Every time a commercial comes on TV, I get up and do maybe one task such as scour the sink, clean the toilet, sweep the floor, get the dishes soaking in super hot water, etc.

I have a cleaning team come in every two weeks. I find ways to carve out the money for that because I know I just can't do it alone. I was gifted with a Roomba, and I let that run every day. I use the dishwasher. I have a cart to take my laundry to my building's laundry room, and I send out the heavier laundry I cannot lift or fold myself. Otherwise, I try to keep things organized and neat as I use them.

I live in a small bungalow with a bathroom, kitchen, sitting room and two bedrooms, so I try [to clean] one room at a time with the weekend off.

I do it on the days I have the energy to.

Have You Noticed It's Harder to Get an Appointment Lately?

Thankfully, I see my immunologist on a monthly basis, and she is scheduling ahead so it's not too bad to get an appointment. But if I have to get one as an emergency, forget it. And to see any other specialist is at least a three- to six-month wait.

Definitely long waits to get specialists' appointments. It's just a fact of life now.

Yes, plus factor in the limitations over who insurance will cover, and it's very difficult.

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.

Is There a Connection Between Salivary Cortisol Levels and IVIG?

I have common variable immune deficiency (CVID) and am treated with intravenous immune globulin (IVIG). Does IVIG have any effect on salivary cortisol levels? I've seen research suggesting an impact on serum cortisol, but I'm not sure whether the same applies to salivary testing. Also, is there any known relationship between CVID or IVIG therapy and idiopathic intracranial hypertension?

Abbie: I reached out to Terry O. Harville, MD, PhD, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, and Leslie Vaughan, RPh, CSP, IgCN, chief operations officer for Nufactor, a specialty infusion company, and they advised that IVIG infusions are not known to affect salivary cortisol levels. While there are rare case reports of cortisol changes when IVIG is given with corticosteroids, these effects are likely due to the steroids rather than the IVIG itself.

CVID and IVIG infusions can both contribute to increased intracranial pressure, sometimes causing symptoms similar to altitude sickness. There are a few rare reports of idiopathic intracranial hypertension following IVIG therapy, most often in patients treated for autoimmune conditions such as juvenile dermatomyositis, but these cases are extremely uncommon.

How Can I Locate a Neuropsychiatrist to Treat My Son?

My adult son has pediatric acute-onset neuropsychiatric syndrome (PANS), autoimmune encephalitis (AE) and immune dysregulation. How can I find a neuropsychiatrist or immunopsychiatrist who understands and treats these conditions? We live in Minnesota, but I'm wondering if specialists in other states can offer telehealth appointments for patients outside their state. Are there specific steps or resources I can use to locate qualified doctors who treat these disorders?

Abbie: Finding a neuropsychiatrist or immunopsychiatrist who understands conditions such as PANS, AE and immune dysregulation can be difficult, but there are several practical ways to begin your search.

1) Identify the right specialty. Focus on physicians who practice in neuroimmunology, autoimmune neurology or neuropsychiatry. These fields are most familiar with the overlap between the immune system and the brain. Large medical centers and teaching hospitals are often the best places to start, since they are more likely to have physicians who treat complex or rare disorders.

2) Understand telehealth and licensing. Telehealth laws differ from state to state. In most cases, a physician must be licensed in the state where the patient is physically located during the appointment. Some specialists are licensed in multiple states through the Interstate Medical Licensure Compact (IMLC), which includes Minnesota. If you find a specialist in another state, ask whether they participate in the IMLC or can see out-of-state patients via telehealth. Some physicians may also work with a local doctor to share care.

3) Find qualified physicians:

- Check the directories at the Autoimmune Encephalitis Alliance (aealliance.org) and the PANDAS Physicians Network (pandasppn.org), both of which list doctors who treat immune-related neurological or psychiatric disorders.
- Use the "Find a Doctor" tools on the American Academy of Neurology or the American Psychiatric Association websites, and search by subspecialty.
- Ask your primary care provider or immunologist for referrals; they often know which specialists are comfortable treating immune-based neurological conditions.

4) Contact offices. When calling or emailing, explain that your son has PANS, AE and immune dysregulation, and that you're seeking a physician who treats neuropsychiatric symptoms connected to immune dysfunction. Ask whether the doctor provides telehealth appointments and if they are permitted to see patients outside their state.

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

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Navigating Life with an Invisible Illness

By Mairead McConnell, PhD

SOME ILLNESSES and ailments are readily apparent and visible, such as wearing a cast on a broken bone, using mobility aids or other external identifiers. Invisible illnesses, however, are not externally obvious. The term invisible refers to the reality that, to an observer, a person may appear healthy, while struggling internally — whether with an autoimmune condition, immunodeficiency or a mental health challenge. The invisibility of the condition may lead to experiences of invalidation, being misunderstood or doubted by loved ones or doctors, and facing unrealistic expectations from others, or even of oneself. While all types of illness can take an emotional toll, living with an invisible condition can uniquely impact one's sense of self and the connection with those around them. If you relate to this experience, consider the steps below to help you navigate these challenges and honor your own needs.

Remember that your story is yours. Any and all information about your health is part of your personal story — one that deserves privacy and respect. Yet when your condition is not visible, you may feel more pressure to explain — or even prove — yourself to others. People in your life may ask questions, some out of genuine care and some out of curiosity, and it can feel tricky to know what to say and who will understand. Know that you get to choose what you share, how much and with whom; you don't owe anyone your story. For those instances when you don't want to disclose, consider preparing a short, kind statement that expresses what you need without saying more than you are comfortable sharing.

> *Any and all information about your health is part of your personal story — one that deserves privacy and respect.*

Know that two things can be true. Invisible illness — like many things in life — has both pros and cons. On one hand, you are not instantly identified and associated with your illness, while on the other hand, your symptoms may be questioned or minimized. This paradox can create a sense of disconnection — between how you feel and how others perceive you. Know that you can appreciate the invisibility and still wish your experience were more easily understood. Living with an invisible illness means learning to hold seemingly opposing truths at the same time.

Release the guilt. It is common for people living with invisible illness to describe feelings of guilt — guilt for needing to cancel plans, for needing help and sometimes for both being sick and "not sick enough." When guilt creeps in, notice it. Ask yourself: Am I actually doing something wrong, or do I have unrealistically high expectations of someone in my position? Your worth is not measured by your productivity, consistency or your ability to "push through."

Practice self-compassion. When your body is unpredictable or doesn't meet the external expectations, it can be easy to jump to criticism or self-blame. Healing means shifting from criticism to care. If this doesn't come naturally, start small: Notice your inner dialogue. Ask yourself what you would say to a friend in the same situation. Maybe you would remind that person that he or she deserves rest, that struggling doesn't erase his or her strength or simply that you love that person, however he or she feels that day. Take a deep breath and offer yourself the same grace you would offer a friend: You deserve it, too.

Living with an invisible illness means learning to navigate both strength and softness. It's an ongoing practice of honoring your limits, protecting your energy and remembering that your worth is not defined by how well you appear to be doing. With patience and self-compassion, you can build a life that honors both your limits and your strength. 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 FDA approved for 3 indications:

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

Pfizer | octapharma®

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

PP-PAN-USA-0927

April 2024

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

CONSUMER BRIEF SUMMARY

(PANZYGA: *pan-zee-guh*)

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

What is PANZYGA?

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).

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

By Terry O. Harville, MD, PhD

IN THE last issue, we introduced the need for vaccination to deal with the COVID-19 pandemic. The Pfizer-BioNTech mRNA vaccine was the first vaccine, authorized on Dec. 10, 2020, nearly a year after the onset of the pandemic, and it had an immediate beneficial impact. The initial death rate due to COVID-19 was approximately 12.9 percent, and it was higher in certain age groups and populations. It is estimated that more than 20 million lives were saved during the first year of vaccination. An estimated 14.8 million life-years were saved (one life-year saved per 900 vaccine doses administered), with the greatest benefit in those ages 60 years and older or with immunocompromising conditions. Ultimately, due to vaccination, the death rate from COVID-19 fell to less than one percent. Thus, despite the politicization, COVID-19 vaccination was critical for saving lives and allowing us all to eventually return to a more pre-pandemic state of living.

Subsequently, additional benefits of COVID-19 vaccination have been found. Those with cancer taking an mRNA vaccine have better outcomes regarding their cancer. Vaccination helps prevent long COVID from occurring. Children receiving a COVID mRNA vaccine are also less likely to develop long COVID, and more recently, it has been found that children receiving a COVID mRNA vaccine are less likely to develop cardiac problems from COVID-19. Furthermore, children with atopic dermatitis are protected from developing infections and further allergic disease. The list of benefits goes on and on despite those who have tried to politicize COVID-19 vaccination as somehow bad. They are wrong! Yet, at the beginning, it was not clear what was going to ensue.

As mentioned in the last issue, progress had been occurring with the concept of mRNA vaccines for a couple of decades since the initial SARS outbreak. Thus, once the "sequence" of the SARS-CoV-2 positive-sense single-stranded RNA was known, "specific" gene components could be used to make an mRNA vaccine. The two initial major developers decided on the "spike protein" for one (Moderna) and the "receptor-binding domain" (RBD) of the spike protein for the other (Pfizer-BioNTech). The vaccines were made based on the concept that these are the regions of the virus that bind to cells for entry into cells. As such, making a neutralizing antibody against these components was considered the way to prevent the entry of the virus into cells and thereby prevent infection. What was not apparently considered was the cellular target for the binding and potential adverse consequences of anti-idiotypic autoimmunity directed to ACE2.

As previously discussed, SARS-CoV-2 enters cells by binding to the cell-surface protein ACE2. Furthermore, autoimmune anti-idiotypic antibodies are made to ACE2 from COVID-19 infection, as well as due to vaccination. Thus, we had concerns that the use of the spike protein or the RBD as the target of the vaccine for antibody production could induce anti-ACE2 antibodies, with potential deleterious effects, based on how the immune system works with regard to the "Jerne Network Theory," even before we were able to demonstrate that anti-ACE2 autoantibodies do occur. While this is true and a major problem for natural infection, serendipity came into play regarding vaccination. (An old saying in medicine is: "At times, it is better to be lucky than good.")

For those with normal functioning immunity, once the production of anti-ACE2 antibodies begins after vaccination, the immune system appears to recognize it is producing autoantibodies and then shuts off the antibody production. Thus, it helps to prevent the adverse processes associated with anti-ACE2 antibodies, as well as other autoimmune antibodies, which are generated during COVID-19 infection. As a consequence, though, we have only a few months of effective antibodies against SARS-CoV-2 and need revaccination every three or four months to maintain antibody protection. Fortunately, though, the T lymphocyte responsive immunity becomes strong and long-lasting. As a result of all this, vaccination does not prevent infection from occurring, but does greatly diminish the risk of dying.

There is much more to discuss about COVID-19 vaccination in the next issue.

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

Understanding the Difference Between Primary Immune and Autoimmune Disorders

By Michelle Greer, RN, IgCN

THE HUMAN immune system is complex and unique, shaped by each person's genetic makeup, environmental exposure, previous infections and personal lifestyle and health habits. It is constantly at work to keep the body (self) healthy and protect it from anything that should not be there such as bacteria, viruses, precancerous or cancerous cells and toxins (nonself).

The various cells, tissues and organs in the immune system all play a role in protecting self. However, sometimes this system is compromised due to a genetic disorder or an outside factor that causes it to malfunction, causing disorder and disease. The immune system can malfunction by becoming underactive, as in primary immune deficiency (PI), or overactive, as in autoimmune disorders.

Underactive Immune System

An *underactive* immune system is known as an immunodeficiency. This means there is a deficiency in the quantity or quality of immune cells. There are primary immune deficiencies (PI), which are a group of more than 550 genetic, inborn disorders[1] that are usually present from birth (but can present later in life as well), and secondary immune deficiencies, which happen when the immune system is compromised by an external factor. In secondary immune disorders, the cause can be identified and usually rectified. Medications, treatments (such as chemotherapy) or viruses (such as HIV), as well as stress, poor nutrition and exposure to environmental toxins are common causes.

PI cannot be cured. The hallmark of PI is recurrent infections, which are more severe, unusual or difficult to treat and may not respond well to antibiotics. At first, many PIs present as "routine" infections (often, infection of the sinuses, ears and lungs) and, therefore, may go undetected in the primary care setting. In fact, it often takes years to make an official diagnosis of PI. PIs may present at any age, and the accurate and timely diagnosis requires a high index of suspicion and specialized testing. Therefore, consultation with a clinical immunologist who is experienced in the evaluation and management of immune deficiencies is essential, since early diagnosis and treatment are critical for preventing significant disease-associated morbidity and improving patient outcomes.[2]

Treatment is based on the specific PI diagnosis, and can include immune globulin (IG) replacement therapy, stem cell or bone marrow transplant, antibiotics as an active or prophylactic therapy, or gene therapy (in severe cases of severe combined immune deficiencies). The mainstay therapy for most B-cell (antibody-deficiency) disorders is intravenous IG (IVIG) or subcutaneous IG replacement therapy; in fact, many patients will require this treatment indefinitely.[2] Lifestyle and supportive care is encouraged for all patients and includes proper nutrition, basic infection prevention measures and stress reduction.

Overactive Immune System

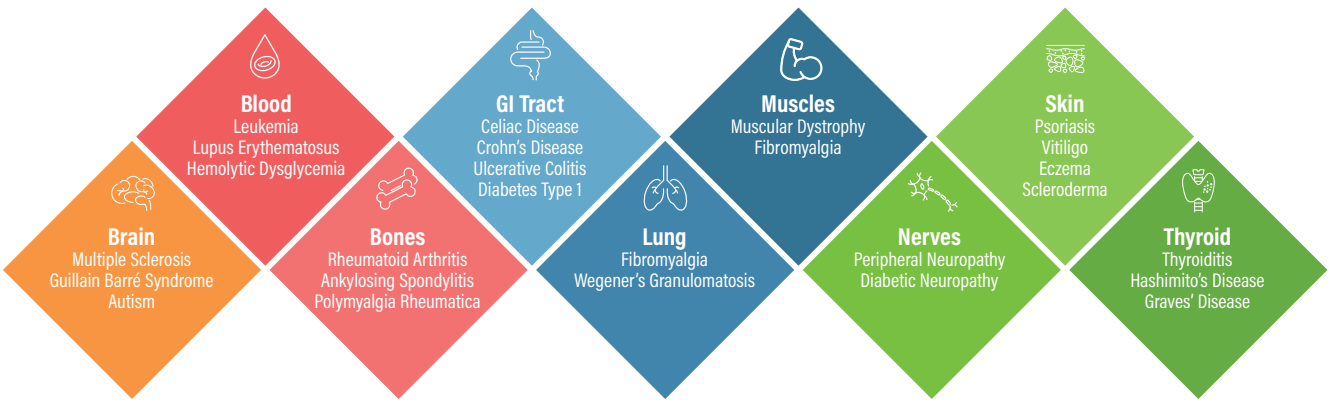
An *overactive* immune system fails to differentiate between self and nonself; it starts an immune response against self, causing inflammation and damage. This can result in autoimmune disease or allergic responses.

In a normal immune response, B cells produce antibodies to bind to a pathogen to mark it for destruction. In an autoimmune condition, B cells produce autoantibodies — antibodies against self — that bind to healthy cells, which signals an immune response. The result is inflammation that can be acute and/or chronic, tissue damage and destruction, and loss of function.

The Autoimmune Association states there are more than 100 known autoimmune diseases (Figure).[3] Autoimmune attacks can occur in any part of any system in the body, and they are chronic, with periods of remissions and relapses. Symptoms and presentation depend on where the attack takes place. Some autoimmune diseases are extremely rare, while others are seen more frequently. Common autoimmune conditions include rheumatoid arthritis (affecting joints), Crohn's disease (affecting the intestinal tract) and type 1 diabetes (affecting insulin-producing islet cells in the pancreas).

Treatment depends on the specific autoimmune disease and may include immunosuppressive agents, biologic therapies, IVIG or plasmapheresis. Prednisone, a corticosteroid medication that can reduce inflammation quickly, is commonly

Figure: Autoimmune Diseases



used. Symptomatic treatment is also used, again depending on the organ involved. For example, insulin therapy is used in type 1 diabetes. As with PIs, lifestyle and supportive care is encouraged for all patients and includes proper nutrition, exercise and stress reduction, as well as avoiding anything known to trigger a relapse of symptoms.

Overlap Between PI and Autoimmune Disorders

While PIs and autoimmune conditions are distinctly different, there can be some overlap. Patients with a PI have an increased susceptibility to infectious diseases and noninfectious complications, including allergies, malignancies and autoimmune diseases. In many cases, autoimmune disease is the first manifestation of PI. The high prevalence of autoimmune disease in immunodeficiencies has increased the suspicion of the presence of common mechanisms.[4] And, some PIs are associated with autoimmune disease due to the dysregulation of the immune system as a whole.[5]

Treatment

Treatment of PI and autoimmune diseases is similar in some cases. Some therapeutic agents such as IG therapy are used to treat both conditions. In PI, IG is used as a *replacement* therapy, meaning it supplies the body with what the immune system doesn't produce on its own. However, in autoimmune disease, IG therapy is used to suppress the overactive immune response; this is known as immunomodulation. The mechanism of action depends on the autoimmune disease, and can involve saturating Fc receptors on immune cells or inhibiting complement activation, which is part of an immune response.

IG therapy dosing is calculated by body weight. Dosing for replacement therapy requires enough IG to replace what the body lacks, while dosing for immunomodulation has a wider range. However, dosing in autoimmune disease is typically much higher than in PI to produce the desired effect of suppressing the immune response.

Optimizing Outcomes

Both PI and autoimmune disorders involve a malfunction of the immune system, and although they represent fundamentally different immune dysfunctions, there can be overlap between the two conditions, and they can occur simultaneously in one patient. Understanding these similarities and distinctions is crucial for accurate diagnosis, effective treatment and optimizing patient outcomes — and, ultimately, improving patients' quality of life.

References

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2. McCusker C, Upton J, and Warrington, R. Primary Immunodeficiency. *Allergy, Asthma & Clinical Immunology*, 2018 Sep 12;14(Suppl 2):61. Accessed at pubmed.ncbi.nlm.nih.gov/30275850.
3. Autoimmune Association. Autoimmune Disease List. Accessed at autoimmune.org/disease-information.
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5. Lehman, HK. Autoimmunity and Immune Dysregulation in Primary Immune Deficiency Disorders. *Current Allergy and Asthma Reports*, 2015 Sep;15(9):53. Accessed at pubmed.ncbi.nlm.nih.gov/26233425.

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MEDICINES

Takeda's HyHub and HyHub Duo Devices Now Available in the U.S.

The recently U.S. Food and Drug Administration-approved HyHub and HyHub Duo devices are now available in the U.S. for patients 17 years of age and older who are prescribed HYQVIA (immune globulin infusion [human] 10% with recombinant human hyaluronidase). The dedicated devices allow HYQVIA, a facilitated subcutaneous immune globulin (SCIG) infusion comprised of dual vial units (DVUs) of immune globulin and hyaluronidase, to be transferred from vials without using a needle or pooling bag in a home environment or clinical setting.

HyHub and HyHub Duo reduce the number of steps required to prepare the IG and hyaluronidase of the HYQVIA infusion by up to half compared to infusing with a pooling bag, depending on the device and number of DVUs used. HyHub and HyHub Duo also reduce the ancillary supplies required to prepare the infusion, and a dedicated carrier bag is available for convenience that enables limited mobility, such as moving from room to room. IG

HyHub™ and HyHub™ Duo Devices Now Available in the U.S. to Simplify HYQVIA® Infusion Preparation. Takeda press release, Oct. 27, 2025. Accessed at www.morningstar.com/news/business-wire/20251027576733/hyhub-and-hyhub-duo-devices-now-available-in-the-us-to-simplify-hyqvia-infusion-preparation.

MEDICINES

FDA Approves First Gene Therapy Treatment for Wiskott-Aldrich Syndrome

The U.S. Food and Drug Administration (FDA) has approved Waskyra (etuvetidigene autotemcel), the first cell-based gene therapy for the treatment of Wiskott-Aldrich syndrome (WAS). Waskyra is indicated for pediatric patients 6 months and older and adults with WAS who have a mutation in the WAS gene and for whom hematopoietic stem cell transplantation (HSCT) is appropriate and no suitable human leukocyte antigen (HLA)-matched related stem cell donor is available.

The safety and effectiveness of Waskyra was assessed based on two open-label, single-arm, multinational clinical studies and an expanded access program totaling 27 patients with severe WAS, which demonstrate substantial and sustained clinical benefit for patients with severe WAS, with significant reductions in the primary disease manifestations that drive morbidity and mortality.

The rate of severe infections decreased by 93 percent in the six to 18 months post-treatment period compared to the rate 12 months before treatment. Similarly, moderate and severe bleeding events were reduced by 60 percent in the first 12 months post-treatment compared to the year prior to treatment. Most patients did not report moderate to severe bleeding after four years post-treatment.

The most common side effects associated with Waskyra include rash, respiratory tract infection, febrile neutropenia, catheter-related infection, vomiting, diarrhea, liver injury and petechiae.

"Today's approval addresses the urgent need in the WAS community, where patients have described living 'a life of terrifying worry and fear' without any approved therapies available," said Vijay Kumar, MD, acting director of the CBER Office of Therapeutic Products. "This action marks significant progress in the development of much-needed treatment options for patients affected by this debilitating and life-threatening disease, enabling them to engage in everyday activities such as going to school or participating in sports."

FDA Approves First Gene Therapy Treatment for Wiskott-Aldrich Syndrome. U.S. Food and Drug Administration press release, Dec. 9, 2025. Accessed at www.fda.gov/news-events/press-announcements/fda-approves-first-gene-therapy-treatment-wiskott-aldrich-syndrome.

MEDICINES

FDA Accepts NDA for Leniolisib to Treat Children with APDS

The U.S. Food and Drug Administration (FDA) has accepted Pharming Group's supplemental new drug application (NDA) for leniolisib to treat activated phosphoinositide 3-kinase delta syndrome, or APDS, in children aged 4 to 11 years. There are no approved treatments in this age group for APDS, a rare primary immunodeficiency caused by variants in PIK3CD or PIK3R1, which is vital to immune cell development and function.

Leniolisib (Joenja) is an oral, selective phosphoinositide 3-kinase delta inhibitor that inhibits the production of phosphatidylinositol-3-4-5-trisphosphate, an important cellular messenger that regulates cell proliferation and differentiation, cytokine production, cell survival, angiogenesis and metabolism.

The supplemental NDA is based on data from a multinational, single-arm Phase III trial in children aged 4 to 11 years who experienced measurable reductions in lymphadenopathy and a statistically significant increase in naïve B cells over 12 weeks, indicating the underlying immune defect was being corrected. Also, the application included safety data from eight months of treatment.

"The study demonstrated clinically meaningful results in both efficacy endpoints and was generally safe and well-tolerated by the 21 patients," said Anurag Relan, MD, chief medical officer at Pharming Group.

Patients experienced these improvements across all four dose levels in the study, Dr. Relan noted, adding that these findings were consistent with benefits seen in adolescent and adult patients as well. FDA approved leniolisib for patients aged 12 years and older in March 2023.

A Prescription Drug User Fee Act date was set for Jan. 31, 2026.

Gawel, R. FDA Accepts Supplemental New Drug Application for Leniolisib for Children with APDS. Healio, Oct. 20, 2025. Accessed at www.healio.com/news/allergy-asthma/20251019/fda-accepts-supplemental-new-drug-application-for-leniolisib-for-children-with-apds.

RESEARCH

A New Study Links Lupus to Common Virus

A new study found a mechanistic link between Epstein-Barr virus (EBV) and lupus. William Robinson, MD, PhD, a professor of medicine in the division of immunology and rheumatology at Stanford University led the study, which provided evidence on how EBV may be the driving force behind lupus.

"Most people [with EBV] are infected as children or as teenagers — EBV is the cause of mono — and approximately 95 percent of people worldwide are infected by the time they are adults," said Dr. Robinson. But after infection, EBV hides in a small number of B cells, which are the immune cells that make antibodies. "Most of the time, these infected B cells remain quiet, but in some people, EBV can reprogram these cells, changing their behavior, how they interact with other immune cells and what antigens they present," he explained.

The study showed that in healthy individuals, there are fewer than one in 10,000 of EBV-infected B cells containing a dormant EBV viral genome. However, the number of EBV-infected B cells in people with lupus increased to approximately one in 400, which is 25 times higher.

"This was a striking and unexpected result," Dr. Robinson said. "It shows that people with lupus have 25-fold more EBV-infected B cells circulating in their blood than healthy individuals. Even though these cells are rare, in our paper we show that they act as over-active 'instigators' of the autoimmune response that mediates lupus."

Researchers also discovered that dormant EBV in a B cell can sometimes create the pro-inflammatory viral protein EBNA2. "Our data show that EBNA2 — a viral regulatory protein expressed in certain latency phases — can bind and activate genes that induce B cells to become pro-inflammatory and activate broad autoimmune responses that mediate lupus," Dr. Robinson explained. "EBV also expresses other genes that activate B cells, and these other genes may also contribute to EBV reprogramming B cells to activate the autoimmune responses that mediate lupus."

Dr. Robinson said he believes these findings may lead to more treatments, and possibly a cure, for lupus in the future.

Pelc, C. Study Links Lupus to Common Virus that Infects 95% of Adults. Medical News Today, Nov. 19, 2025. Accessed at www.medicalnewstoday.com/articles/study-links-autoimmune-lupus-common-virus-epstein-barr-infection.

MEDICINES

Bispecific Antibodies Signal a New Era for Autoimmune Disease Treatment

According to a report in the *New England Journal of Medicine*, the bispecific antibody teclistamab induces prolonged remission in patients with some autoimmune diseases who do not respond to other treatments. In some cases, one course of therapy eliminates the need for daily medication for several months, and remission may last up to a year in some patients.

Bispecific antibodies such as teclistamab are a new approach to autoimmune therapy: It is a bispecific T-cell engager that links T cells to B cells, including those producing harmful antibodies. This connection signals T cells to eliminate malfunctioning B cells, potentially restoring immune balance and reducing the need for ongoing immune suppression. Bispecific antibodies have demonstrated efficacy in blood cancers such as multiple myeloma and lymphomas, providing drug-free remissions. Early data suggest teclistamab may reset the immune system, extending beyond symptom control.

Most patients experience mild, short-term side effects, including low-grade cytokine release syndrome, which causes fever or aches. Some develop minor, manageable infections. No severe neurological complications or life-threatening events are reported.

Clinical trials for teclistamab in systemic sclerosis and rheumatoid arthritis are underway in Europe and the United States. These studies aim to determine the optimal dosing, duration of remission and patient selection criteria. Long-term follow-up will assess the effects of repeat dosing and the potential for sustained health without ongoing treatment.

Haseltine, WA. Bispecific Antibodies Signal a New Era for Autoimmune Disease Treatment. Forbes, Nov. 4, 2025. Accessed at www.forbes.com/sites/williamhaseltine/2025/11/04/bispecific-antibodies-signal-a-new-era-for-autoimmune-disease-treatment.

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.

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.

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.

0008-01-2024 3/2024

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Top 20 IG Living Articles: *Readers' Choice*

20th Anniversary Issue

We asked, and you answered!
Here are the top 20 articles that have most helped readers over the past 20 years.

Autoimmunity in Common Variable Immune Deficiency

A host of autoimmune disorders are the most common complications of CVID that are lifelong yet responsive to treatment.

www.igliving.com/magazine/full-Issues/IGL_2020-10_Full-Issue.pdf#page=36

Cutaneous Cues: What Your Skin May Be Trying to Tell You

Your skin is the largest organ in your body, and it has a lot to say about your health. Therefore, it is important to pay close attention to it, especially if you have a primary immune deficiency.

www.igliving.com/magazine/full-Issues/IGL_2025-06_Full-Issue.pdf#page=34

Diagnosing and Treating CVID

CVID may be the most common type of severe antibody deficiency or primary immunodeficiency, and an earlier diagnosis allows for more effective treatment.

www.igliving.com/magazine/full-Issues/IGL_2025-06_Full-Issue.pdf#page=48

The Effects of Exercise on Fatigue and Stamina

Science has documented the short- and long-term effects of exercise for both healthy and patient populations. But before beginning an exercise program, it must be tailored for each individual.

www.igliving.com/magazine/articles/IGL_2011-04_AR_The-Effects-of-Exercise-on-Fatigue-and-Stamina.pdf

Fibroymyalgia: The Mystery of Chronic Pain

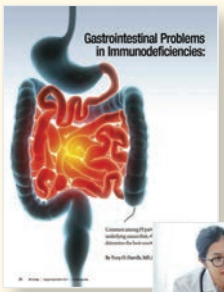
The journey of one patient's quest to be treated for fibromyalgia shows how difficult the condition is to diagnose due to its complex symptoms and a healthcare environment that often prevents providers from both seeing and treating these patients.

www.igliving.com/magazine/articles/IGL_2013-06_AR_Fibromyalgia-The-Mystery-of-Chronic-Pain.pdf

Foods to Combat GI Distress

While many foods can ease gastrointestinal distress, others can exacerbate it, so individuals need to assess their individual tolerability.

www.igliving.com/magazine/full-Issues/IGL_2021-08_Full-Issue.pdf#page=34



Gastrointestinal Problems in Immunodeficiencies

Common among PI patients, leaky gut has many underlying causes that, when identified, can determine the best course of treatment.

www.igliving.com/magazine/articles/IGL_2017-08_AR_Gastrointestinal-Problems-in-Immunodeficiencies-What-Is-Leaky-Gut.pdf

How to Handle Medical Setbacks

Many strategies can help you cope when your health takes a downturn, but the key is reacting to it in a proactive manner to help you get through it.

www.igliving.com/magazine/full-Issues/IGL_2025-02_Full-Issue.pdf#page=34

Medical Gaslighting: A Growing Concern in Modern Healthcare

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

www.igliving.com/magazine/full-Issues/IGL_2025-12_Full-Issue.pdf#page=24

Navigating and Negotiating Medical Bills

Do medical bills leave you scratching your head in confusion or pulling out your hair in frustration? Here's how to make sense of what you owe and why you owe it.

www.igliving.com/magazine/full-Issues/IGL_2024-12_Full-Issue.pdf#page=36

Navigating Your First IVIG Infusion

Being well-prepared for your first infusion can help to ensure a successful outcome. These tips can prepare you for every step of the journey.

www.igliving.com/magazine/full-Issues/IGL_2025-02_Full-Issue.pdf#page=24

No More Nodding and Smiling: How to Become a Proactive Patient

Are you feeling like a passive participant in your healthcare? Now is the time to take control of your well-being and transform yourself into a proactive patient.

www.igliving.com/magazine/full-Issues/IGL_2024-02_Full-Issue.pdf#page=30

Nurturing in Nature

The emotional and physical benefits of nature can be easily harnessed with the five senses no matter where one is located.

www.igliving.com/magazine/full-Issues/IGL_2025-06_Full-Issue.pdf#page=38

Planes, Trains and Automobiles: Traveling with IG Therapy

Travel is stressful, but it can be even *more* stressful when managing a chronic health condition. These five tips can help.

www.igliving.com/magazine/full-Issues/IGL_2024-04_Full-Issue.pdf#page=28

Practicing Self-Care Without Guilt

Learning to put your own needs ahead of everyone else's is a challenge for even the healthiest. When chronic illness is a factor, the hurdles are even higher.

www.igliving.com/magazine/articles/IGL_2018-08_AR_Practicing-Self-Care-Without-Guilt.pdf

Rediscovering Joy: Embracing the Art of Having Fun

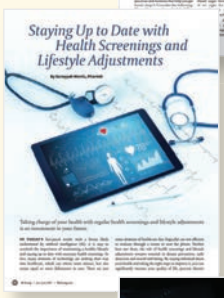
Approaching life with a sense of playfulness and whimsy isn't just fun; it's also good for your health.

www.igliving.com/magazine/full-Issues/IGL_2025-04_Full-Issue.pdf#page=26

Sleep Aids

Adding sleep aids to your nightly routine can help you get more of the sleep you need. Refer to the products in our shopping guide for items that are generally considered safe.

www.igliving.com/magazine/articles/IGL_2025-08_AR_Sleep-Aids.pdf



Staying Up to Date with Health Screenings and Lifestyle Adjustments

Taking charge of your health with regular health screenings and lifestyle adjustments is an investment in your future.

www.igliving.com/magazine/full-Issues/IGL_2025-06_Full-Issue.pdf#page=30

Sleep's Powerful Effects on the Immune System

Sleep and immunity are closely linked. Here's why consistent, restorative sleep is imperative for maintaining good health.

www.igliving.com/magazine/full-Issues/IGL_2023-06_Full-Issue.pdf#page=40

Transitioning Your IG Coverage to Medicare

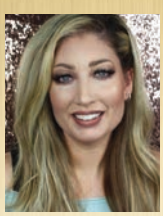
Medicare coverage options can be more complicated than IG therapy, but these guidelines can help to ensure a smooth transition.

www.igliving.com/magazine/articles/IGL_2025-10_AR_Transitioning-Your-IG-Coverage-to-Medicare.pdf

IG Living: 20th Anniversary Issue Special Feature

Top 20 Patient Profiles

Over the past 20 years, *IG Living* magazine has featured 120 individuals' stories in our Let's Talk column. While we think all of these profiles deserve to be highlighted, we have selected one from each year to help mark our 20th anniversary. The links to the profiles on the IG Living website are provided so you can read the ones that intrigue you the most; maybe that will be all of them!



2025: JASMINE AHUMADA

Jasmine Ahumada was an active 27-year-old with a career she loved when her life took a dramatic turn. After chronic illness and a serious staph infection left her hospitalized and grappling for answers, Jasmine was eventually diagnosed with common variable immune deficiency. Unable to work, the California resident began to dabble in makeup artistry, a move that launched an entirely new career. She has been featured globally in print, news and television for her creativity, even appearing on the TV show "The Doctors." Going viral online also led Jasmine to become more active in speaking about patient advocacy.

www.igliving.com/magazine/articles/IGL_2025-04_AR_Lets-Talk-Jasmine-Ahumada.pdf

2024: RORY DUCKWORTH

As the founder and owner of the Salt Lake Triathlon Club, Rory Duckworth has defied the odds when it comes to what is possible when living with an immune disease. He was diagnosed with common variable immune deficiency but not until he was 30 years old. Today, he is a USA Triathlon-certified and Ironman-certified coach, with a passion for swimming, cycling, running and helping others. Through his work as a coach and event organizer, Rory aims to create inclusive, supportive environments where everyone can experience the joy and personal growth that comes from crossing a finish line.

www.igliving.com/magazine/articles/IGL_2024-06_AR_Lets-Talk-Rory-Duckworth.pdf

2023: MADISON "MADDIE" SHAW

Madison "Maddie" Shaw's journey to a common variable immune deficiency diagnosis took place over a frustrating two and a half years that included acute infections, multiple hospitalizations and almost two dozen doctors. In the end, it was Maddie's mom, Tracy, who noticed a poster in an airport that finally led them to an accurate diagnosis. Today, Maddie is a college graduate and award-winning rare disease advocate, while Tracy serves as chair of the board of trustees at the Immune Deficiency Foundation. This dynamic mother/daughter duo continues to raise funds and awareness within the rare disease community, and they are passionate about helping others find their voice.

www.igliving.com/magazine/articles/IGL_2023-10_AR_Lets-Talk-Madison-Maddie-Shaw.pdf

2022: HARPER SPERO

Harper Spero is a business coach who specializes in working with service-based solopreneurs and small business owners. She is also the founder of Made Visible, a 100-episode podcast that has evolved into a writing platform that helps people living with or affected by invisible illness share their stories. A New York City-based writer who focuses on chronicling her rare immunodeficiency, hyper IgE/Job syndrome, Harper's work has been featured by Thrive Global, Fast Company, Scary Mommy, Career Contessa, Jewish Book Council and "The Today Show."

www.igliving.com/magazine/articles/IGL_2022-04_AR_Lets-Talk-Harper-Spero.pdf

2021: CAMERON AND MAX MONA

Like many families living with an immune deficiency disease, the Mona family found abundant support through the Immune Deficiency Foundation. That's why when siblings Cameron and Max decided they wanted to raise money for their favorite nonprofit and also boost awareness about Cameron's common variable immune deficiency diagnosis, they decided to "go big or go home." An avid mountain climber, Max floated the idea of trekking Mount Kilimanjaro, and right away the brothers knew they had found their fundraiser. In July 2019, after rigorous preparation and training, Max reached both his fundraising goal and the summit, successfully paying tribute to the little brother he considers his "hero."

www.igliving.com/magazine/articles/IGL_2021-04_AR_Lets-Talk-Cameron-and-Max-Mona.pdf

2020: CARL SCHLACHT

As a retired professional motorcycle racer turned insurance agent and entrepreneur, Carl Schlacht is a prime example of someone who refuses to let chronic illness hold him back. The 35-year-old Cleveland, Ohio, resident was diagnosed with X-linked agammaglobulinemia (XLA) as an infant, but he has gone on to defy the odds by pursuing his dream to compete in extreme sports. Today, he is an insurance agent, filmmaker and, never getting enough of extreme sports, rally car racer.

www.igliving.com/magazine/articles/IGL_2020-02_AR_Lets-Talk-Carl-Schlacht.pdf

2019: ELLA CASANO

Ella Casano was diagnosed with idiopathic thrombocytopenic purpura when she was 7 years old. Ella's diagnosis requires her to receive intravenous (IV) immune globulin infusions every eight weeks, a prospect that was initially daunting for a young child. But, in a classic "turn-lemons-into-lemonade" scenario, her childhood fear of the IV bag became the inspiration for an invention that is bringing comfort to children around the country. We chatted with Ella's mom, Meg Casano, to learn more about her entrepreneurial daughter and her innovative idea: Medi Teddy.

www.igliving.com/magazine/articles/IGL_2019-10_AR_Lets-Talk-Ella-Casano.pdf

2018: KEEGAN AND LAURA CONCANNON

Keegan Concannon was diagnosed with common variable immune deficiency (CVID) as a toddler. At 13 years old, this incredibly resilient young man not only fought alongside his parents to obtain VGo robotic technology in his Hudson, Mass., school district, he also defied his physical setbacks and became part of a local football team. We chatted with Keegan and his mom, Laura, to learn more about this family's hurdles and their commitment to keeping CVID from defining Keegan or limiting his accomplishments.

www.igliving.com/magazine/articles/IGL_2018-06_AR_Lets-Talk-Keegan-and-Laura-Concannon.pdf

2017: KELLY BRUSKI

Kelly and Kyle Bruski's two young sons, 7-year-old Taylor and 3-year-old Colton, have an inherited immune disorder that requires monthly infusions of immune globulin. And, although the family could get treatments closer to home, they travel 500 miles to get treatment by the staff they have bonded with at the Billings Clinic pediatric infusion room. Touched by the outpouring of support they have received, Kelly raised $1,000 to purchase Cuddle Bear books by Claire Freedman and Gavin Scott, and the bear plush toys that go with them, donating these items to children who have to go through the same thing her boys do.

www.igliving.com/magazine/articles/IGL_2017-06_AR_Lets-Talk-Kelly-Bruski.pdf

Hizentra®
Immune Globulin Subcutaneous (Human) 20% Liquid

PREFILLED SYRINGES

ELEVATE YOUR EXPERIENCE

Discover proven protection with a first and only for Ig—
Hizentra Prefilled Syringes

Important Safety Information

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

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

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

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

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

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

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

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

Please see Brief Summary of full Prescribing Information on reverse.

Available in **1 g, 2 g, 4 g,** and **10 g**—the largest size ever for Ig

Simple, convenient, and ready to use

- Simplifies infusion preparation vs vials
- Wide range of sizes for your individual needs
- Select sizes are directly compatible with common infusion pumps
  - – All sizes can be transferred to a pump syringe using a syringe-to-syringe transfer device

"I am very grateful for the simplicity that prefilled syringes provide, even for someone like me who has limited strength in their hands."

—**Angela**, patient advocate on Hizentra*

Learn more about Hizentra prefilled syringes at **Hizentra.com/elevate**

*Patient advocates are not healthcare professionals or medical experts. For medical questions, please contact your physician. Patient advocates are compensated by CSL Behring LLC for their time and/or expenses.

Ig=immune globulin.

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

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

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

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

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

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

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.

CSL Behring

Satisfaction was high with the first and only Ig prefilled syringes

In a CSL-sponsored Harris Poll survey of 33 people with PI who have used prefilled syringes*

At least **97%** were very/somewhat satisfied with:

- **Ability to personalize treatment**
- **Overall convenience**
- **Overall ease of administration**
- **Ability to fit treatment into their lifestyle**

Exclusively from Hizentra

Ask your doctor if self-infusing with prefilled syringes might be right for you. Learn more at **Hizentra.com/elevate**

*In an online survey, at least 32 of 33 people who self-infused Ig in prefilled syringes were very/somewhat satisfied on all measures mentioned.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Based on April 2023 version.

Hizentra is manufactured by CSL Behring AG and distributed by CSL Behring LLC.
Hizentra® is a registered trademark of CSL Behring AG.

CSL Behring

2016: JULIE FETCH

Since her diagnosis of common variable immune deficiency, Julie Fetch went from frustrated patient to hands-on political advocate. In 2010, Fetch and several other patients met with legislators in Washington, D.C., a move that led to the sponsorship of House Bill HR 2002, the Medicare Patient IVIG Access Act. Fetch traveled again to D.C., speaking out regarding the Medicare Part B cost-cutting proposal that could adversely impact patients' access to lifesaving and life-enhancing Medicare Part B-covered therapies such as intravenous immune globulin.
www.igliving.com/magazine/full-issues/IGL_2016-08_Full-Issue.pdf#page=38

2015: JENNIFER PATE, MD

As a teenager, Jennifer Pate had ambitions of making the professional tennis circuit, when a series of recurrent infections relegated her to the sidelines. Her eventual diagnosis of common variable immune deficiency changed the course of her life and her career plans. Today, Dr. Pate is a recognized psychiatrist and was named repeatedly in lists of America's top psychiatrists. Today, she specializes in the treatment of complex and life-threatening illnesses and in helping the chronically ill cope with their diagnosis.
www.igliving.com/magazine/full-issues/IGL_2015-08_Full-Issue.pdf#page=38

2014: LAURA BRINTON

As a registered nurse, Laura Brinton is accustomed to dealing with illness every day. But, when she was diagnosed with common variable immune deficiency, the tables were turned. Rather than allow the diagnosis to derail her career, Laura embraced it as an opportunity to provide more compassionate care. According to Laura, "When we have patients with chronic pain issues, I totally get it. Chronic pain is very hard to treat most of the time, and I feel like I can listen, give advice, hold their hand and provide better support; I am living in that same situation."
www.igliving.com/magazine/full-issues/IGL_2014-02_Full-Issue.pdf#page=34

2013: DEB STANZAK

Deb Stanzak is the founder of RonWear Port-able Clothing. After several years of personal tragedy, Deb founded RonWear with the hope of helping people who receive infusion treatments. Her brother, Ron, was a noncompliant diabetic with complications that included renal failure that required three dialysis treatments a week. Before Ron passed away in 2005, he made Deb promise she would develop the idea, and in 2008, she did. RonWear is a specially designed line of clothing with zippered openings to accommodate ports for dialysis, infusions or chemotherapy. www.igliving.com/magazine/full-issues/IGL_2013-04_Full-Issue.pdf#page=34

2012: TYLER CARLSON

Sickly since birth, Tyler had gone undiagnosed until the fifth grade, when doctors finally determined he was suffering from common variable immune deficiency (CVID). Tyler came to our attention when we saw a Facebook post he made looking for patients willing to be interviewed for a documentary he was making to make a difference in the lives of those diagnosed with chronic disease. His project, Swimming Against the Tide: Living with CVID, was an effort to get the word out there for all to see and hear, and to be the voice of those who don't know how to explain it. www.igliving.com/magazine/full-Issues/IGL_2012-06_Full-Issue.pdf#page=36

2011: STEVEN SMITH

Many who rely on immune globulin treatments to sustain them physically also have discovered the power of support groups to sustain them emotionally. Steven Smith, a co-leader for a Manhattan-based neuropathy support group, has chronic inflammatory demyelinating polyneuropathy. He provides his group members with inspiration, encouragement and connection. Whether members are depressed from a recent diagnosis or are seasoned attendees, Steven points them to the tools and resources they need to live life to the fullest.
www.igliving.com/magazine/full-Issues/IGL_2011-06_Full-Issue.pdf#page=34

2010: JAMES AND CONNIE RAMOS

After James and Connie Ramos' two children were diagnosed with primary immunodeficiency, the couple committed to learning everything they could about the disease. Then, they went a step further by dedicating themselves to funding research and expanding awareness to help other families facing similar challenges. With the support of their physician and All Children's Hospital in St. Petersburg, Fla., James and Connie established the Southeast Primary Immunodeficiency Network under the umbrella of the Jeffrey Modell Foundation. Starting a nonprofit organization is a huge undertaking for anyone; for the parents of two chronically ill children under the age of 10, it was positively heroic.

www.igliving.com/magazine/full-Issues/IGL_2010-08_Full-Issue.pdf#page=32

2009: JOANE PEASE

Joanne Pease is the mother of three sons who have X-linked agammaglobulinemia, a rare immunodeficiency that occurs in about one in 250,000 males. Unaware that her sons had the disease, two of them were given the standard vaccinations, including the live vaccines. Unfortunately, one son contracted mumps after receiving the live mumps vaccine and another contracted polio after receiving the live polio vaccine. That led Joanne to testify at a Senate hearing to discontinue live vaccines. As a result of her testimony, the live polio vaccine is no longer given.

www.igliving.com/magazine/full-Issues/IGL_2009-08_Full-Issue.pdf#page=30

2008: STACY AND ANDY

Stacy is the mother of Andy who has ataxia telangiectasia (A-T), a rare inherited disease that affects physical abilities and can affect the immune system. Andy's sister, Cassy, also had A-T, as well as a compromised immune system that required immune globulin therapy. Cassy died from A-T due to complications. To help raise funds for A-T, Andy went skydiving and raised over $1,000 for AT Children's project.

www.igliving.com/magazine/full-Issues/IGL_2008-02_Full-Issue.pdf#page=27

2007: BARBARA YODICE

Barbara Yodice is a multiple autoimmune disease patient, including sarcoidosis, myasthenia gravis and five others. After finding that many of the rare autoimmune diseases have no national organization, she founded the Autoimmune Information Network that provides immediate and direct individualized assistance to patients, finds doctors and sources for obtaining insurance or paying for medication, helps with disability claims, runs local support groups, goes to doctors with patients and provides expert witness testimony. One hundred percent of the money donated to the organization goes to autoimmune patients.

www.igliving.com/magazine/full-Issues/IGL_2008-12_Full-Issue.pdf#page=13

2006: TINA MORGAN

Tina Morgan is a Canadian citizen who was diagnosed at 16 years of age with common variable immune deficiency after multiple illnesses that started at just 1 month old. When there was a blood shortage in 1998, Canadian patients who needed blood products such as immune globulin were unable to get their treatments. Since there was no organization in Canada to represent the needs of primary immune deficiency patients, she established the Canadian Immunodeficiencies Patient Organization in her kitchen, and it's still helping patients to this day.

www.igliving.com/magazine/full-Issues/IGL_2006-10_Full-Issue.pdf#page=38

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Could it be your immune system?

Immune Deficiency Foundation

Take the self-assessment to find out if your symptoms could point to a primary immunodeficiency (PI). It's an informative way to gather insights that you can discuss with your healthcare provider.

idf.primaryimmune.org/immunetest

Immune Deficiency Foundation FILMS

compromised.

[life without immunity]

Follow the heart-wrenching yet hopeful stories of those living with a primary immunodeficiency.

A must-watch documentary.

Learn more: idf.primaryimmune.org/watchfilm

ADVOCACY. EDUCATION. RESEARCH.
A COMMUNITY EMPOWERED

Whether you've been recently diagnosed, have been living with a primary immunodeficiency (PI) for years, or just think you might have a PI, the Immune Deficiency Foundation is here to help.

While PI has no cure, there are lifesaving treatments available that can improve your quality of life. Our programs are meant to connect, engage, and empower families to live longer, stronger, healthier lives.

SCAN ME

Immune Deficiency Foundation

primaryimmune.org | idf@primaryimmune.org

Chronic Illness Lifestyle:
Creating Routines That Support Your Health

Honoring your body and organizing your days are important parts of disease management.

By Rachel Maier, MS

IF YOU HAVE been diagnosed with a chronic illness, you are likely well aware that healthy habits are an important part of your disease management plan. You may take prescription medication or receive a specialty therapeutic to address your condition, but your body needs more than medicines to help you be as healthy as you can be. Nutritious food, movement, sleep and social support, for example, all contribute to a healthier you. In fact, clinicians recommend incorporating healthy routines into your daily life to support better health overall because they can help you manage your condition and prevent further complications. "As clinicians, we want you to find ways to make routines that support better health," said Cheryl Beutell, APRN, a psychiatric nurse practitioner at Northwestern Medicine. "Having a routine is how you build habits. When we practice good habits, that can help us maintain positive relationships, good hygiene and our best health."[1]

But making healthy habits a part of your everyday life can feel intimidating. Implementing a lot of change at once is overwhelming, and bad habits are hard to break. The best way to make healthy habits part of your chronic illness lifestyle is to first create a personalized, realistic routine that fits into your life and supports your unique health goals. This takes intention, planning and persistence. Yes, it's work — but it's work that pays off.

Habit vs. Routine

Habits and routines are related, but their differences are important to understand:

- Habits are single actions performed so often that they become almost involuntary. These are the things we do without even thinking about them such as washing hands after using the toilet, putting on a seatbelt, hitting the snooze button, brushing teeth before bed, etc. We do them without putting much thought into whether we feel like doing them or not. In fact, *not* doing them can make us feel bad.
- Routines are a series of actions performed repeatedly in a particular order for a particular purpose. These are things we may not feel like doing in the moment such as waking up early, exercising and eating a protein-packed breakfast before getting ready for work. Doing them might feel uncomfortable in the moment because the routine often sacrifices what we want right now (extra sleep) with what we know is best for us (exercise). With time and repetition, routines can turn into habits.

Motivation Matters

Anyone can create a healthy routine, but you must have one important thing to implement one: *motivation*. You must first see the benefits of creating healthy routines in your life. Then, you must want the payoff. When you are motivated,

you are more able to stick to routines that cause temporary discomfort (such as exercising instead of hitting the snooze button) because you believe the benefits are worth it (increased strength, improved heart health, etc.). It all starts in your mind.

The good news? Routines usually aren't difficult forever. With time and effort, all the good things you do for your body will become nearly second nature and, eventually, it won't be such a struggle to get them done. In fact, you will start to feel "off" when you don't do them, and that's a sign that routines have become habits.

Five Reasons to Create a Healthy Routine

In case you need more convincing, here are five more reasons creating daily routines can help support a healthy lifestyle, even with unique hardships that come with managing a chronic illness.

Healthy routines:[3,4,5]

1) Reinforce medication adherence. Nonadherence to medication can lead to poor management of chronic disease and a higher healthcare burden.

2) Help reduce the amount of decisions you make during the day, which in turn reduces decision fatigue. Decision fatigue can drain your energy, diminish self-control and increase anxiety, depression, regret and guilt.

3) Empower you to make better choices. Routines help you make decisions ahead of time, which helps you make better decisions overall.

4) Build consistency. Engaging in healthy behaviors once in a while is good, but engaging in healthy behaviors consistently is better.

5) Contribute to a better quality of life and a longer life expectancy.

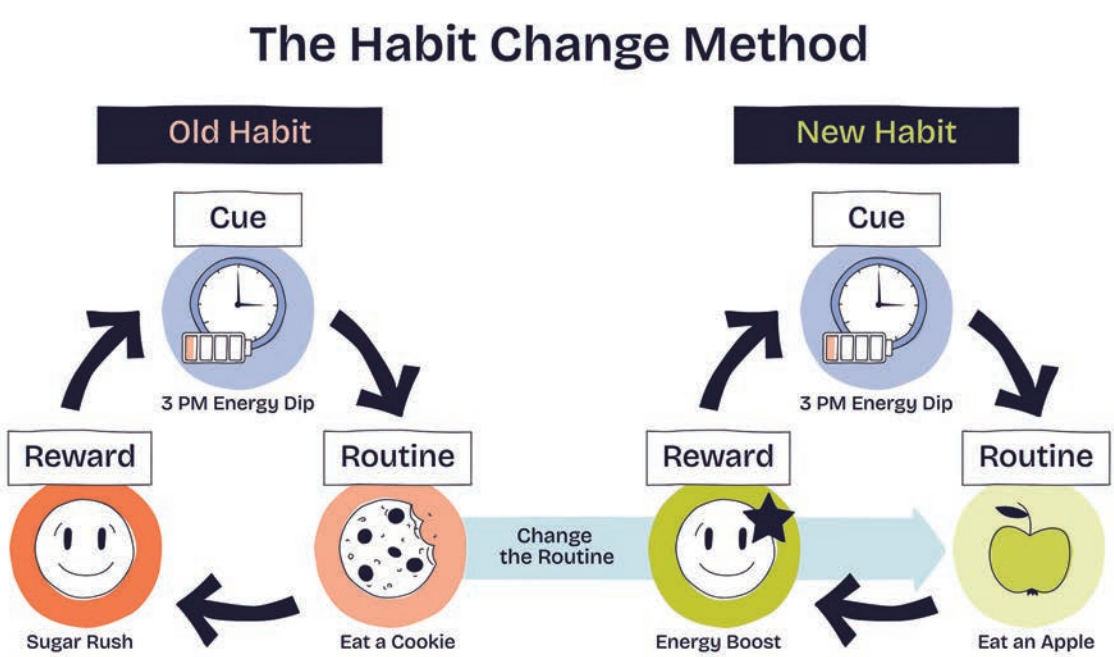
How to Create a Routine That Works for You

The best part about creating a routine can also be the most frustrating: What actions you include and how you organize them in your day is entirely up to you. While general principles of healthy routines apply to everyone (prioritize movement, nutrition, sleep and stress-reducing activities), your life is uniquely your own, and the way you live it is up to you. Your routine may look very different from mine, and that's OK.

Here's how to create a routine that aligns with your needs, preferences and responsibilities:

1) *First, ask yourself, "What do I need?"* Routines won't stick unless they serve you well. Take inventory of what your body, mind and schedule need. Think about your symptoms, energy levels and triggers, as well as your roles, responsibilities and preferences. Ask yourself questions such as:[2]

- What time of day do you tend to have the most energy?
- What tasks and activities are challenging for you?
- How much rest does your body need?
- What does your schedule look like during this season of



octagam® 10%

Immune Globulin
Intravenous (Human) 10%
Liquid Preparation

For the treatment of dermatomyositis (DM) in adults

INDICATIONS AND USAGE

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

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

IMPORTANT SAFETY INFORMATION

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

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

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

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

79%

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

68%

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

32%

Major improvement
vs 8% placebo
(secondary endpoint)

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

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

Most common drug-related side effects

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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Distributed by Pfizer Labs, Division of Pfizer Inc.

 PP-OTG-USA-0396 February 2025

octagam® 10%

Immune Globulin
Intravenous (Human) 10%
Liquid Preparation

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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Distributed by Pfizer Labs, Division of Pfizer Inc.

your life?

- What helps keep your mind sharp, clear and focused?
- What are your roles and responsibilities during a normal day?
- Do you have any bad habits you need to replace with new, healthy habits?

2) *Set specific, realistic goals.* Routines are not the same as goals, but identifying a few health goals may help inform and shape your routine. For example, maybe you recognize your body needs more sleep. *Go to bed early* could be your goal, but it's a vague one. Make your goal more specific, making sure it's also realistic: *Get eight hours of sleep every night.* To make this routine stick, you could decide you will turn lights off by 10:00 p.m. and set the alarm clock for 6:30 a.m. This routine is both specific and realistic: It doesn't force you to go to bed too early, but it also sets aside a little more than eight hours for sleep so you have time for falling asleep, waking up to use the bathroom overnight, etc. Your routines should be manageable, not overwhelming. Build in flexibility so it's easier to stick with your routine.

3) *Make a framework.* Routines involve performing the same activities repeatedly in a particular order, but they don't necessarily need to be tied to a particular time of day. Consider making a framework for your routine instead of a schedule, and use it to plan the order in which you will complete certain activities.

Here's a sample framework to get you started thinking about how you might set one up for yourself:

- Morning routine: Start the day with activities that support your body. Take your medicine, eat a nutritious breakfast, exercise, drink a glass of water, etc.
- Midday routine: Spend the day completing tasks that need to be done: go to work, run errands, attend appointments, clean your house, return emails. Make time for feeding yourself a nutritious lunch, and make space for a short nap if you know your body needs one.
- Evening routine: End the day by winding down: spend time with loved ones; engage in a hobby; share a meal; watch a show or read a book; engage in self-care (skin care, stretching, meditation, etc.); prepare for tomorrow (lay out clothes, pack your lunch); go to bed.

Remember: Your routine should be unique to you — what you need, what you prefer and how you spend your days. For example, do you like to exercise in the morning? If so, do you work out before breakfast or after breakfast? Or are mornings already busy and evening workouts work better for you? Do you leave the house for work? Work from home? Are you retired? Do you volunteer? The answer to all of these questions (and so many more) play a role in determining when various activities will realistically fit into your framework. For example, my healthy routine framework includes a morning walk. If I don't take one in the morning, I know I won't have time or energy to take one at all. However, my walk isn't tied to a specific time on the clock.

4) *Be flexible*. If you are a person who thrives on schedules, then by all means, create one as part of your routine. You can tie your routines to certain times of the day if you want to. However, you don't have to schedule your days down to the minute to reap the benefits of creating a healthy routine. Your framework should be flexible because you have a wild card: your chronic illness. Your energy will fluctuate, and some days will be better than others. You might need to adjust your plans based on your symptoms or energy level, and that's OK. The great thing about a framework (and not a schedule) is that you can follow your routine regardless of how your schedule changes. For example, you can still do your evening routine on nights when you need to get to bed early; you'll just do your routine earlier than on a typical day.

Make Time for What Matters

You are so much more than your illness, but sometimes it feels like your illness likes to run the show, doesn't it? No doubt, everything is harder when your body suffers from chronic illness. Everyday activities that are easy for others can be very difficult for you, and your body can only go so far or take so much before it breaks down. You might have plenty of good days — and I sure hope you do! — but you'll have some not-so-good days, too. Creating healthy routines doesn't prevent the bad days from happening, but healthy routines do set you up for taking good care of your body so you can live the best possible version of your life, given your unique circumstances. Make the time to prioritize your health. You are worth the effort and investment! IG

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From Fatigue to Focus:
Practical Tips for Living Well with Chronic Immune Conditions

When you manage multiple conditions, keeping up with your health feels like a full-time job! Here are some ideas to help you handle it well.

By Janelle Salo, RN

IT CAN BE exhausting just trying to keep up with chronic immune globulin (IG) disorders. Between doctor visits, treatments and managing daily symptoms, it's easy to feel like your health is running the show. The truth is, you're doing way more than most people realize, and that's something to be proud of! But managing it all is still a lot of work. Here are some practical tips for making it a little bit easier.

IG Conditions 101

Chronic IG disorders such as common variable immune deficiency (CVID)[1] or IgG deficiency[2] happen when your body doesn't make enough antibodies to fight off infections. That means you might get sick more often or stay sick longer than other people. It's not your fault; it's how your immune system works, and treatments like intravenous IG (IVIG)[3] therapy can help boost your defenses.

On top of IG disorders, many patients also juggle overlapping conditions such as autoimmune issues. Symptoms such as gut problems, fatigue or even anxiety can make it difficult to determine which symptom originates from where.[4] It's like dealing with a health puzzle where the pieces don't always fit neatly together. Symptoms often blur together, making it tricky to pin down what's really going on. Fatigue, pain or brain fog might come from your immune disorder or from something else entirely. That overlap makes diagnosis, treatment and even daily tracking a real challenge.

The Struggles No One Talks About

Fragmented care. Managing multiple chronic conditions often means juggling several specialists who don't always talk to each other. You end up being the messenger, carrying notes and test results from one office to the next. It can feel like your care is in pieces instead of working together.

Overlapping symptoms. When you're dealing with fatigue, brain fog or pain, it's tough to know what condition or treatment is causing it. Symptoms overlap so much that it's like chasing shadows, which can be extremely frustrating. This makes it harder to explain what's going on to your providers as well.

Multiple medications. Taking several medications can feel like a balancing act. One might help your immune system but upset your stomach, while another eases pain but causes fatigue. Keeping track of doses, side effects and possible interactions is basically another job.

Lack of clear answers. Sometimes even your doctors don't have all the answers, especially when conditions interact in complicated ways. You might hear different opinions from different specialists, leaving you stuck in the middle. It's confusing, and it often feels like everyone expects you to figure it out on your own.

Insurance stress. Even when you and your doctor agree on the best treatment, insurance companies can throw roadblocks in the way. Prior authorizations, denials and high out-of-pocket costs add stress you don't need. Sometimes it feels like you spend more time fighting for care than actually receiving it.

Building a Whole-Person, Team-Based Approach

Sometimes it feels like your health is divided into slices of a pie: one specialist gets this slice, another gets that slice and so forth. But you deserve coordinated care in which every provider sees you as a whole person, not just the condition that landed you in their office. You are more than one specialist's slice of the healthcare pie. When your doctors consider their slice in light of the whole, and actually talk to each other, it makes managing your care way less overwhelming. At the end of the day, your care should fit together, because your life isn't divided into specialties.

What whole-person care looks like. Whole-person care means treating more than just your symptoms;[5] it's about supporting your mind, body and lifestyle as a whole. It can look like your immunologist working with your therapist, or your doctor asking you about stress, sleep and nutrition, not just looking at lab results. The goal is to build a care plan that actually fits your life, not one that feels like a checklist.

Coordinated communication between providers. When your doctors share information and talk to each other about you, your care feels smoother and less stressful. You get fewer mixed messages, and you don't have to play the go-between. That way, you can spend more energy on your health instead of chasing down updates.

Inclusion of mental health, nutrition and social support.

When your healthcare team listens to what matters to you, your treatment starts to feel more personal and empowering.

Caring for your health isn't just about tests or medications; it's about your mind, body and community, too. Paying attention to your mental health, moving your body, eating well and surrounding yourself with supportive people can make a huge difference in how you feel on a day-to-day basis. When you take care of all parts of yourself, everything starts to work together a little more smoothly.

Listening to your personal goals. Your goals matter just as much as your lab results. Maybe you want more energy to hang out with friends or enough strength to get back to a

hobby you love — that's what your care should focus on. When your healthcare team listens to what matters to you, your treatment starts to feel more personal and empowering.

How to Get Your Dream Team on the Same Page

Getting your healthcare team on the same page starts with communication. Share updates, test results and medication lists with all your healthcare providers so everyone is informed about your care. Don't be afraid to ask your doctors to connect directly when they work together; your care becomes far more coordinated and less stressful for you.

1) Choose a "point person." Having one main provider, such as your immunologist or primary care doctor, helps keep everything organized. He or she can track the big picture, share updates with other specialists, and ensure nothing slips through the cracks. It's like having a team captain who helps everyone play from the same game plan.

2) Use a shared patient portal. If your healthcare system offers a shared patient portal, use it. It's a total game-changer! You can message your doctors, track test results and make sure everyone is on the same page. It keeps all your information in one place, so you spend less time repeating yourself and more time focusing on feeling better.

3) Bring written updates or summaries to every visit. Give your providers a quick summary at each appointment to help them see the whole picture quickly. You can jot down any new symptoms, medication changes or questions since your last visit. It keeps things clear and ensures you leave with real answers instead of more confusion.

4) Ask providers to send notes to one another. Don't be shy about asking them to share their notes; it's part of good care! When your specialists swap updates, they can spot connections and avoid overlapping treatments. It saves you from having to explain everything twice and helps everyone stay on the same page.

5) Bring an advocate to appointments. Caregivers or trusted friends can make a big difference. They help take notes, ask the questions you might forget and remind you later what was discussed. It's always easier to stay organized and feel supported when you have someone in your corner.

Medication Management Is No Joke

Managing medications when you have more than one condition can feel like a full-time job. It's easy to lose track and worry about combining medications that shouldn't be mixed. Keeping an updated list and double-checking with your doctor or pharmacist helps you stay safe and ensure your treatments work as intended.

Medication juggling. The more conditions you manage, the more medications you're likely to be taking; it adds up quickly. Keeping track of what to take, when to take it and how each one interacts with the others can get confusing. Stay organized with a simple hand-written list or an app to help you stay on top of it and avoid mix-ups.

Unexpected problems. When you're taking multiple medications, it's easy for side effects, drug interactions or treatment interference to sneak up. Sometimes, a new medication can exacerbate an old symptom, or two prescriptions may not interact well. That's why checking in regularly with your doctor or pharmacist is so important. They can catch issues before they turn into bigger problems.

Drug interactions. If you're taking two or more medications and they affect each other in ways that change how they work or how you feel, you may be having a drug interaction.[6] Some combinations can make a medicine less effective, while others can cause unexpected side effects. Always let your doctor and pharmacist know about all the medications you are taking, including supplements and over-the-counter products, so they can help you stay safe.

Conflicting treatments. Sometimes treatments can work against each other, such as when one medication boosts your immune system while another tries to calm it down. It's frustrating and can leave you wondering which one to prioritize. Talking openly with your care team helps them find the right balance so each treatment supports your overall health.

Duplicated medications. It's surprisingly easy to end up with duplicate medications, especially when you're seeing

different specialists. One doctor might prescribe something similar to what another doctor has already given you without realizing it. Keeping a current medication list and sharing it at every appointment helps prevent medication overlap and ensures your treatment plan remains safe and streamlined.

Keeping an updated medication list and double-checking with your doctor or pharmacist helps you stay safe and ensure your treatments work as intended.

Tips for Managing Medications Safely and Effectively

Staying on top of your medications doesn't have to be stressful; you need a sound system. Use a medication tracker or pill organizer, and set reminders on your phone to keep your schedule straight. Always double-check with your doctor or pharmacist before adding any new medication to ensure your safety and that everything works together effectively.

Keeping an updated medication list is one of the easiest ways to stay organized and informed. Write down each medication, the dose, who prescribed it and what it's for. Bring it to every appointment so your doctors can quickly spot any issues or overlaps.

Before starting any new medication, ask:

- Will this interact with my other medications? Even simple vitamins or over-the-counter medications can cause unexpected reactions, so it's worth double-checking with your doctor or pharmacist.
- Will this affect my immune system? Some medications can either boost or suppress your immune response. Knowing how a medication will affect your immune system is especially important if you already have an IG deficiency.
- How does this fit into my overall care plan? Every treatment should support your big-picture health goals, not complicate them, so make sure your care team helps you see how it all connects.

Tools That Can Help You Stay on Track

Technology can make managing your health a lot easier! From symptom trackers to medication reminder apps, these tools help you stay organized and spot patterns your doctors might miss. Find the ones that fit your lifestyle, and let your phone do some of the heavy lifting so you can focus on feeling your best.

- Symptom tracker app: Bearable
- Med tracker app: Medisafe
- Note-taking/journaling app: Evernote
- Binder or digital folder: Google Drive
- Drug interaction site: Drug Interaction Checker (Drugs.com)

Final Thought

Managing multiple immune-related chronic conditions isn't easy, but you are stronger and more capable than you probably realize. You navigate symptoms, appointments and uncertainty every day — and you are still moving forward. That kind of strength deserves recognition!

With the right support, good systems and a positive mindset, you can absolutely live a full, healthy life, even when your immune system throws you a few curveballs. Building your care team, staying organized and giving yourself grace make all the difference. You've got more control than you think.

Don't be afraid to speak up, ask questions and set boundaries. It's your body and your journey. Your voice matters in every appointment and every decision. The more you advocate for yourself, the better your care and your peace of mind will be. IG

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Pharmacy Benefit vs. Medical Benefit: What's the Difference?

When it comes to insurance reimbursement for prescription drugs, where you receive medications matters. Here's what you need to know.

By Lee Warren

IF YOU'VE ever looked at your itemized hospital bill and wondered why a medication prescribed in the hospital costs so much more there than a similar medication purchased at your pharmacy, you're not alone. To make matters even more confusing for patients, medication costs can even differ greatly if patients receive them in a hospital outpatient setting instead of a physician's office or at home. For patients with health insurance with high deductibles or high out-of-pocket maximums, such differences in cost can have a huge impact on the family budget.

The root of this confusion comes down to two separate components within your health insurance plan: the pharmacy benefit and the medical benefit. Understanding the difference can help you make more informed — and more affordable — healthcare decisions.

Pharmacy Benefit

The pharmacy benefit of a patient's healthcare insurance plan covers outpatient prescriptions. Usually, these benefits are managed by pharmacy benefit managers (PBMs), who are third-party administrators hired by health insurance companies, employers or other entities.[1] PBMs process prescription claims, set formularies and negotiate prescription drug prices with manufacturers.

Pharmacy benefits have their own deductibles, co-payments and out-of-pocket maximums. Since PBMs work for health insurance companies or organizations that provide health insurance for their employees, this can create tension for patients if cost-control measures lead to certain medications being more expensive or, sometimes, harder to access. Some plans require patients to obtain self-administered specialty drugs through an in-network specialty pharmacy to receive full coverage. Failure to do so will lead to higher out-of-pocket costs.

Medical Benefit

The medical benefit of a patient's healthcare insurance plan covers medications and treatments administered by a healthcare professional in a hospital, infusion center, physician's office or at home. With medical benefits, healthcare providers bill the patient's insurance directly. Deductibles and coinsurance may be different from what the patient pays at the pharmacy. Medications billed under the medical benefit often have higher out-of-pocket costs because patients pay a percentage of the medication's cost (coinsurance) until they meet their annual deductible or out-of-pocket maximum. This is different than pharmacy benefits, for which patients are more likely to have a set co-pay, making prescriptions more affordable and predictable.

Medical benefits often cover high-cost specialty medications, including infusions for autoimmune conditions such as rheumatoid arthritis or Crohn's disease, as well as essential therapies for immune deficiency disorders such as immune globulin. But that doesn't mean patients won't have to pay

anything. It just means specialty drugs are billed under the medical side of their insurance plan rather than the pharmacy side. Patients will still have out-of-pocket responsibilities, and often, those costs can be substantial.

Understanding the Terms

Before diving into ways you can reduce your medication costs, it's important to understand a few key terms that often affect your out-of-pocket expenses. Knowing these will empower you to ask the right questions and make cost-saving decisions about your care.

- *Site of care* refers to the place your medication is administered, such as a hospital outpatient center, doctor office or at home — and each location may be billed differently to your insurance by the different providers.
- *Specialty pharmacies* focus on complex, high-cost medications and often provide additional support services, such as nurse counseling, and help navigate insurance approvals, providing the supplies necessary for infusable or injectable medications and coordination of nursing care when applicable.
- *Co-pay assistance programs*, typically offered by pharmaceutical manufacturers or foundations, are designed to help eligible patients lower their out-of-pocket costs for expensive medications.

Why Prices Differ

One of the factors contributing to higher costs on the medical benefit side can be attributed to facility fees. These are extra charges added by hospitals or hospital-owned outpatient facilities or clinics to cover operational costs, such as building maintenance, equipment and essential staff. Twenty states have passed legislation that addresses or limits facility fees.[2]

Negotiated rates between insurers and providers are another contributing factor. Insurance companies contract individually with hospitals, clinics and pharmacies. Prices can differ for the same medication or service. The negotiated prices are considered trade secrets.[3] One hospital might negotiate a higher reimbursement rate than a community clinic, and a specialty pharmacy might offer a lower contracted price due to volume-based discounts.

Also, site-of-care markup is in play, which is different than facility fees. Facility fees are separate charges. Site-of-care markup is the increased base cost of a drug or treatment that is charged by certain hospitals or hospital-owned clinics because hospitals negotiate higher reimbursement rates with insurance companies. Also, the drug or treatment is billed under medical benefit billing codes instead of pharmacy benefit codes.

One source says that infusions administered in hospitals can cost three to five times as much as infusions administered in in-office or freestanding ambulatory settings.[4] And, an industry overview noted that the average cost per infusion in a hospital outpatient setting ranged from $5,500 to $11,500, while the same treatment in a physician office or ambulatory infusion center ranged from $3,500 to $5,000.[5] Depending on your insurance plan, the final out-of-pocket cost could be significantly different, depending on the benefit.

The Emotional and Financial Toll

For people living with immune deficiency disorders or autoimmune diseases, the stress of managing a chronic condition is often compounded by financial uncertainty. Many rely on regular infusions, injections or specialty medications essential to maintaining their health, and yet the cost of each treatment can vary dramatically depending on how it is billed.

For patients with immune deficiency disorders, missing even a single infusion can increase infection risk, while for those with autoimmune conditions, delayed or skipped treatments can trigger flares or hospitalizations.

Infusions administered in hospitals can cost three to five times as much as infusions administered in in-office or freestanding ambulatory settings.

All this unpredictability and uncertainty can lead to what healthcare experts call "financial toxicity,"[6] in which anxiety about potential costs causes patients to experience emotional distress, delays in care or skipped treatments. When patients better understand how their medications are covered under their health plan, they are more likely to adhere to treatment, plan ahead financially and regain a sense of control over their

WITH XEMBIFY FOR PI,

COUNT ON MORE GOOD DAYS

XEMBIFY is a highly purified SCIG that contains ≥ 98% IgG and is designed to replace what your body doesn't make itself.[1,2]

IgG, immunoglobulin G; PI, primary immunodeficiency disease; SCIG, subcutaneous immunoglobulin.

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS

- **Thrombosis (formation of blood clots within blood vessels) may occur with immune globulin products, including XEMBIFY. Before you take XEMBIFY, talk to your doctor if you:**
  - **Are older**
  - **Are sedentary (need to lie down or sit down) for long periods of time**
  - **Are taking estrogen-containing medicines (birth control pills, hormone replacement therapy)**
  - **Have a permanent intravenous (IV) catheter**
  - **Have hyperviscosity of the blood (diseases such as multiple myeloma or other causes of elevated proteins in the blood)**
  - **Have cardiovascular (heart) problems or previous history of stroke**
- **Thrombosis may occur even if you don't have any risk factors**
- **If you are at risk of thrombosis, your doctor may prescribe XEMBIFY at the minimum dose and infusion rate. Make sure you drink plenty of fluid before taking XEMBIFY. Make sure your doctor is checking you regularly for signs and symptoms of thrombosis and is checking your blood viscosity if you are at risk of hyperviscosity**

What is XEMBIFY®?

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

Who should not use XEMBIFY?

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

What are possible serious side effects of XEMBIFY?

- **Aseptic meningitis syndrome (AMS).** Aseptic meningitis is a non-infectious inflammation of the membranes that cover the brain. It causes a severe headache syndrome, which may occur with human immune globulin treatment, including XEMBIFY. If you are showing signs and symptoms of AMS, your doctor may conduct a thorough neurological evaluation including spinal tap (sampling fluid which surrounds the spinal cord) to rule out other causes of meningitis. Stopping human immune globulin treatment has resulted in the end of signs and symptoms within several days. Treatment may include analgesics (pain medicines) and/or a special procedure known as a "blood patch" to stop headache
- **Hypersensitivity.** Severe allergic reactions may occur with immune globulin products, including XEMBIFY. If you have a

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Xembify® (immune globulin subcutaneous human-klhw) 20%

INFECTION PROTECTION YOU CAN TRUST WITH PROVEN TOLERABILITY[1,3]

In a clinical study, people taking XEMBIFY had[3]:

- **0** serious bacterial infections*†
- **0** hospitalizations due to infection†
- Infection-fighting levels of IgG in an average of 3 days‡

*One patient reported sepsis due to an animal bite, an event deemed unrelated to treatment.[3]
†Rate per subject-year: 0.049.[3]
‡Based on commonly accepted IgG thresholds to prevent infection.[3]

Count on XEMBIFY for the power of pure protection.[1-3]
Scan the code or visit XEMBIFY.com

severe allergic reaction, stop the infusion immediately and get medical attention. XEMBIFY contains IgA. If you have known antibodies to IgA, you may have a greater risk of developing potentially severe allergic reactions

- **Kidney problems or failure.** Kidney problems or failure may occur with use of human immune globulin products, especially those containing sucrose (sugar). XEMBIFY does not contain sucrose. If you have kidney disease or diabetes with kidney involvement, your doctor should perform a blood test to assess your hydration level and kidney function before beginning immune globulin treatment and at appropriate intervals thereafter. If your doctor determines that kidney function is worsening, they may discontinue treatment
- **Hemolysis.** Your doctor should monitor you for symptoms of hemolysis (destruction of red blood cells causing anemia, or low red blood cell count). If your doctor suspects hemolysis, they should perform additional tests to confirm
- **Transfusion-related acute lung injury (TRALI).** TRALI is a rare but serious syndrome characterized by sudden acute respiratory distress following transfusion. If your doctor suspects TRALI, they will monitor you for any other lung issues. TRALI may be managed with oxygen therapy
- **Transmissible infectious agents.** Because XEMBIFY is made from human blood, it may carry a risk of transmitting infectious agents such as viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent. No cases of transmission of viral diseases or CJD have been associated with the use of XEMBIFY
- **Interference with lab tests.** Because XEMBIFY contains a variety of antibodies, blood tests to determine antibody levels may be falsely elevated. Be sure to tell your doctor or lab technician that you are using XEMBIFY

What are other possible side effects of XEMBIFY?

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

Please see brief summary of the full Prescribing Information on the following page or visit XEMBIFY.com for the full Prescribing 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.

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XEMBIFY®

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

HIGHLIGHTS OF PRESCRIBING INFORMATION

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

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

Initial U.S. Approval: 2019

WARNING: THROMBOSIS

See full prescribing information for complete boxed warning.

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

---------- RECENT MAJOR CHANGES ----------

Dosage and Administration, Dose	7/2024
Dosage and Administration, Administration	7/2024

---------- INDICATIONS AND USAGE ----------

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

----------DOSAGE AND ADMINISTRATION ----------

For subcutaneous infusion only

Dose

XEMBIFY can be administered at regular intervals from daily up to every two weeks (biweekly).

- Switching to XEMBIFY from intravenous immune globulin (IVIG): If a patient is switching to XEMBIFY, obtain the patient's serum IgG trough level to guide subsequent dose adjustments.

  Establish the initial weekly dose in grams by converting the monthly (or every 3 weeks) IVIG dose into an equivalent weekly dose and increasing it by using a dose adjustment factor (1.37)

  $$\text{Initial weekly dose (grams)} = \frac{\text{Prior IVIG dose (in grams)} \times 1.37}{\text{Number of weeks between IVIG doses}}$$

  – Weekly: Begin XEMBIFY one week after last IVIG infusion.

  – Frequent dosing (2-7 times per week): Divide the calculated weekly dose by the desired number of times per week.

  – Biweekly dosing (every 2 weeks): Multiply the weekly dose by 2.
- Switching to XEMBIFY from subcutaneous immune globulin (IGSC): Administer the same weekly dose (grams) as the weekly dose of prior IGSC treatment (grams).
- Treatment-naïve patients: For patients starting IgG replacement (not switching from IVIG or IGSC) administer loading doses of 150 mg/kg/day for 5 consecutive days, followed by weekly administrations starting at Day 8 at 150 mg/kg/week. Monitor IgG trough levels frequently every 2 weeks during first 8 weeks.

Administration

Infusion sites: up to 6 infusion sites simultaneously, with at least 2 inches (5 cm) between sites avoiding bony prominences, visible blood vessels, scars, and any areas of inflammation (irritation) or infection. Rotate sites for each administration.

Patient Age	Maximum Volume (mL/infusion site)	Infusion Rate (mL/hr/infusion site)
Children 2 to <10 years	25	≤25
Adults, children ≥10 years	25	≤35

---------- DOSAGE FORMS AND STRENGTHS ----------

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

---------- CONTRAINDICATIONS----------

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

---------- WARNINGS AND PRECAUTIONS----------

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

---------- ADVERSE REACTIONS ----------

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

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

---------- DRUG INTERACTIONS----------

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

---------- USE IN SPECIFIC POPULATIONS ----------

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

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health journey. Clarity doesn't just reduce costs; it reduces fear and supports better outcomes.

Even a small change in billing from pharmacy benefit to medical benefit can mean the difference between a manageable co-pay and an overwhelming bill. For patients already coping with fatigue, infections or flares, navigating these financial hurdles can feel like an additional burden. Gaining clarity about coverage pathways allows patients and caregivers to focus more on healing and less on paperwork and surprise charges.

Take Control of Your Costs

Patients managing chronic immune deficiency or autoimmune conditions often feel trapped by rising medication costs and complicated insurance rules. While you can't change how insurers direct different entities to bill, you often can change where and how you receive your medications.

Rather than being a passive recipient of whatever billing pathway your medication falls into, you can take practical, informed steps to make your treatment more affordable and predictable. By asking the right questions, exploring alternative settings for care and ensuring your medication is billed under the most cost-effective benefit, you can often reduce your out-of-pocket expenses by hundreds or even thousands of dollars each year. The following strategies are designed to help you take an active role in your care without compromising treatment quality.

1) *Ask about site-of-care options.* Not all locations charge the same price for the exact same treatment. Ask your doctor or insurer if the infusion or injection can be administered in a lower-cost setting such as a physician's office, ambulatory infusion center or even at home. This simple shift can reduce costs by thousands of dollars per year.

2) *Explore home infusion or self-administration.* Many specialty medications now have options for home infusion or self-injectables through the pharmacy benefit.[7] These are often significantly less expensive and may offer more predictable co-payments. However, that is slowly changing. Ask if your medication qualifies for home administration and whether training or nursing support is available.

3) *Ask your doctor about therapeutic alternatives.* There may be biosimilars (more affordable alternatives to a specific class of medicines called biologics) or lower-cost medications that are equally effective but billed under your pharmacy benefit instead of the medical benefit, resulting in lower out-of-pocket costs. Your doctor can help you compare options.

4) *Request a good faith estimate before treatment.* You have the right to ask your provider for a good faith estimate of expected charges for a scheduled treatment.[8] If the service is booked at least three business days in advance, federal law requires certain providers to give the written estimate within one business day of scheduling.

5) *Use patient assistance or co-pay support programs.* Many pharmaceutical manufacturers offer co-pay assistance, foundation grants or patient support programs for high-cost medications. Specialty pharmacies (which are often included in your insurance plan's network and can be found in your plan's provider directory) often help with enrollment, but you can also apply directly.

A drug covered under your pharmacy benefit one year may move to your medical benefit the next (or vice versa), affecting your costs.

6) *Check your insurance plan's policies each year.* Benefits can change annually. A drug covered under your pharmacy benefit one year may move to your medical benefit the next (or vice versa), affecting your costs. Reviewing your plan during open enrollment can help you avoid surprises. If you have an agent, check with him or her each year to make sure your prescriptions haven't moved from one benefit to the other.

7) *Work with a care coordinator or patient advocate.* Some insurers offer case managers who specialize in complex medical conditions. They can help navigate approvals, appeals and cost-saving options that patients may not know about. You can also check out the Patient Advocate Foundation (www.patientadvocate.org), which offers free one-on-one support, as well as a co-pay relief program for qualified patients.

By taking these steps, you're not only managing your expenses; you're positioning yourself to stay on top of your health and treatment over the long term.

How Understanding Your Benefits Supports Better Health

Beyond saving money, knowing how your pharmacy and medical benefits work can improve your long-term health. Patients who plan ahead and coordinate with their care team are less likely to experience treatment delays or skipped doses. Over time, this proactive approach can reduce complications, hospitalizations and disease flares associated with immune deficiency or autoimmune conditions. Understanding your benefits isn't just about bills; it's also an investment in staying healthy and maintaining control over your treatment.

Questions to Ask Your Insurance Provider: Pharmacy Benefit

1) Which specialty pharmacies are in-network for my plan?

2) Can my self-injectable or oral specialty medication be filled at my local pharmacy, or must it go through a specific specialty pharmacy?

3) What is my co-pay or coinsurance for this medication under the pharmacy benefit?

4) Does my pharmacy benefit cover biosimilars or lower-cost alternatives?

5) Are there any patient assistance programs, manufacturer co-pay cards or foundations available for my medication?

Questions to Ask Your Insurance Provider: Medical Benefit

1) If I need an infusion or injection at a clinic, hospital or outpatient center, which locations are in-network?

2) What is my deductible, coinsurance or co-pay for medications administered under the medical benefit?

3) Can my medication be administered at home or at a lower-cost infusion center?

4) Does my plan cover alternative therapies or biosimilars under the medical benefit?

5) Can I get an estimate of my out-of-pocket cost before treatment is administered?

Pro Tip

Keep a running list of your specialty medications, including dosage and billing category (pharmacy vs. medical). Periodically review it yourself to ensure it is complete and accurate, especially before open enrollment. Bring the list to appointments with your doctor, specialist, infusion nurse or health insurance agent to verify details and ask questions. Staying organized helps prevent surprise bills and ensures continuity of care.

Ask Questions, Be Empowered

Navigating the differences between pharmacy and medical benefits can feel overwhelming, but understanding how your medications are billed is one of the most effective ways to take control of your healthcare costs. Whether you are managing an immune deficiency, an autoimmune disorder or another chronic condition, knowing the financial options of your treatment allows you to make informed choices, ask proactive questions and avoid unexpected expenses.

You don't have to accept the first option presented to you. You can ask about home infusion, request cost estimates, evaluate pharmacy vs. medical billing and explore financial support programs. These are not just cost-saving strategies; they are keys to ensuring consistent access to the therapies you rely on. When you understand your benefits, you gain more than financial clarity. You also gain peace of mind and the confidence to advocate for your health.

Empowerment in healthcare doesn't come from knowing all the answers; it comes from knowing which questions to ask. By taking the time to understand your coverage, explore your options and work alongside your care team and insurance provider, you can play an active role in your treatment journey. The system may be complex, but with the right knowledge, you can protect your financial well-being and navigate the system with confidence.

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Treating Autoimmune Cytopenias in PI Patients

A significant cause of morbidity in PI patients, early identification is important to guide therapy and prevent complications.

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

AUTOIMMUNE CYTOPENIAS (AICs) are among the most frequent autoimmune complications observed in individuals with primary immune deficiency (PI). They represent a paradox in which an immune system is both underactive in fighting infections and overactive against the body's own cells. In AICs, the immune system mistakenly attacks healthy blood cells, platelets, red blood cells or neutrophils, resulting in conditions such as immune thrombocytopenia (ITP), autoimmune hemolytic anemia (AIHA), autoimmune neutropenia (AIN) or a combination such as Evans syndrome.[1]

Recognizing AICs in PI patients is clinically important. For many patients, cytopenias may be the first sign of immune dysregulation disorder, even before recurrent infections develop, and can be helpful in diagnosing PI.[2] Early identification can guide appropriate therapy, prevent complications of empiric immunosuppression and allow genetic-specific interventions.[3]

Epidemiology

AICs occur in a substantial number of patients with PI. In common variable immune deficiency (CVID), the most common symptomatic primary antibody deficiency, 10 to 20 percent of patients develop AICs during their lifetime, most often with ITP and AIHA.[4,5] Among children with CVID, cytopenias may precede diagnosis of immune deficiency by several years.[6]

Beyond CVID, AICs are a hallmark of several inborn errors of immunity, a group of genetic conditions marked by immune system imbalance. These include CTLA-4 haploinsufficiency, LRBA deficiency, STAT3 gain-of-function (GOF), activated PI3K-delta syndrome (APDS) caused by PIK3CD/PIK3R1 mutations and autoimmune lymphoproliferative syndrome (ALPS).[7,8] In these conditions, immune dysregulation rather than infection predominates, and cytopenias may affect multiple blood cell lines or coexist with lymph node enlargement and organ-specific inflammation.

Data from the European Society for Immunodeficiencies (ESID) registry show that recurrent or refractory autoimmune cytopenias are strongly associated with PI.[9] Additionally, nearly half of children with Evans syndrome have a monogenic immune dysregulation disorder, especially when cytopenias are persistent or resistant to treatment.[10] This has important implications for evaluation and genetic testing.

Clinical Presentation

The manifestations of AICs reflect the specific hematologic lineage targeted by autoimmunity (Table 1):

In contrast with idiopathic AICs, those associated with PI are frequently chronic, treatment-refractory or involve multiple cell lines.[10-13] Many patients also have other immune findings such as persistent lymph node swelling, enlarged spleen (splenomegaly), chronic diarrhea or lung inflammation, which suggests an underlying immune disorder.[14]

Clinical suspicion is further raised when cytopenias coexist with recurrent sinopulmonary infections, poor vaccine responses, family history of autoimmunity or other immune-related organ diseases.[14] Early immunology referral and diagnostic testing are warranted in these scenarios.

Diagnosis

Diagnosis of AICs aims to confirm that the cytopenia is autoimmune and to determine whether a primary immune defect is contributing. A structured evaluation distinguishes AICs from infection-, drug- or marrow-related causes.

Initial evaluation. A thorough history and physical exam remain essential. Key historic indications of AICs associated with PI include chronic, relapsing cytopenias, poor response to standard therapies, family history of immune disease, recurrent infections, swelling of lymph nodes or spleen, chronic diarrhea and failure to thrive in pediatric patients.[15] Baseline laboratory evaluation involves:

Table 1. AICs and Their Hematologic Lineages and Manifestation

Type of Cytopenia	Blood Cell Affected	Common Symptoms
Immune thrombocytopenia (ITP)	Platelets	Pinpoint bruising (petechiae), easy bruising, nose bleeds (epistaxis), gum bleeding or heavy periods Swelling of lymph nodes (lymphadenopathy) or enlarged spleen (splenomegaly)[11]
Autoimmune hemolytic anemia (AIHA)	Red blood cells	Fatigue, pale or yellow skin, dark urine, rapid heartbeat Laboratory findings include elevated reticulocytes (reticulocytosis), indirect elevated bilirubin (hyperbilirubinemia), elevated lactate dehydrogenase (LDH) and positive direct antiglobulin (Coombs) test
Autoimmune neutropenia (AIN)	Neutrophils	Recurrent infections, mouth ulcers, fever
Evans syndrome	Multiple blood cell lines (usually platelets, red blood cells)	Combination of bleeding and anemia symptoms[12]

• Complete blood count (CBC) with differential: confirms cytopenia type and severity

• Reticulocyte count: distinguishes production vs. destruction cause

• Peripheral smear: evaluates morphology and hemolysis

• Direct antiglobulin test (Coombs): confirms AIHA

• LDH, bilirubin, haptoglobin: hemolysis markers

• ESR/CRP: inflammatory markers

• Viral testing: EBV, CMV, parvovirus B19, hepatitis, HIV

• Autoantibodies: Useful in some cases but often negative in PI due to impaired antibody production

Bone marrow examination is reserved for atypical cases or when malignancy or marrow failure is suspected.[15]

Immunologic evaluation. Once immune-mediated cytopenia is established, evaluation for a PI should be strongly considered, especially with multi-cell line involvement, treatment-resistant disease, splenomegaly or other autoimmune features.[17] Core immunologic testing typically includes:

• Immunoglobulin levels (IgG, IgA, IgM)

• Vaccine antibody response testing

• Lymphocyte subsets (CD3, CD4, CD8, CD19, NK cells)

• B-cell memory phenotype (low class-switched memory B cells seen in CVID)

• Flow cytometry: Essential for evaluating lymphocyte populations and detecting double-negative T cells, particularly in suspected ALPS

• Screening for associated autoimmune disorders (thyroiditis, celiac disease)

Autoantibody panels may be negative in PI because antibody production is impaired.[4] In patients already diagnosed with PI, AICs often signal immune dysregulation rather than progressive immune deficiency alone.[4,16]

Genetic testing and monogenic immune dysregulation. Targeted next-generation sequencing panels that include CTLA4, LRBA, STAT1, STAT3, PIK3CD, PIK3R1, FOXP3 and TACI are recommended for refractory or relapsing cytopenias, early-onset disease, Evans syndrome or a strong family history.[7,8] Up to 65 percent of children with Evans syndrome or chronic AICs harbor variants in immune-regulatory genes, which can guide precision therapy such as abatacept for CTLA-4/LRBA deficiency, leniolisib for APDS or JAK inhibitors for STAT1/STAT3 GOF.[9,17]

Differential diagnosis. The diagnosis of AICs in PI requires exclusion of alternative causes:[5]

• Medication-induced cytopenias (example: trimethoprim-sulfamethoxazole, antiepileptics)

• Secondary immune cytopenias from viral infections (EBV, CMV, parvovirus B19)

• Bone marrow failure syndromes (aplastic anemia, myelodysplasia)

• Hypersplenism from chronic lymphoproliferation in CVID or ALPS

• Lymphoid malignancies (rare but increased risk in CVID)

Treatment

Management of AICs focuses on controlling immune-mediated cell destruction while preserving residual immunity and preventing infection.[17]

General treatment principles[4]

1) Restoring safe blood counts to prevent bleeding, anemia-related hypoxia or infection.

2) Minimizing corticosteroid exposure and long-term immunosuppression.

3) Preventing infection through optimization of immune

globulin (IG) replacement and antimicrobial prophylaxis.

4) Treating the underlying immune regulatory defect when identified.

Multidisciplinary collaboration between hematology, immunology and, when indicated, genetics and infectious disease specialists is essential.

First-line therapies

• Corticosteroids remain the initial treatment. Prednisone (1 mg/kg/day) or pulse dexamethasone (40 mg/day × 4 days) can raise counts in roughly 80 percent of cases, though relapses are common.[18] Because PI patients face higher infection risk, clinicians use the lowest effective dose and shortest duration; infection prophylaxis is considered for prolonged courses.[19]

• Intravenous IG (IVIG) serves both as immune protection and as therapy for AICs, often given at 1-2 g/kg with improvement within 24 to 72 hours.[20] Patients already on maintenance IVIG may benefit from an additional dose during relapse. A notable side effect of IVIG is noninfectious hemolysis, which is a risk, particularly in high-dose treatments or in patients with underlying inflammatory conditions, and requires monitoring.

Second-line and steroid-sparing therapies

• Rituximab, an anti-CD20 antibody that depletes B cells, achieves responses in 70 to 85 percent of CVID-associated ITP and AIHA cases, though relapses occur in up to 50 percent.[21] Ongoing IG therapy and infection monitoring are critical after treatment.

• Thrombopoietin receptor agonists (TPO-RAs), such as romiplostim, eltrombopag and avatrombopag, stimulate platelet production and are effective in chronic ITP, including PI-related cases.[25] They are generally well-tolerated, with monitoring for liver function and thrombosis.[22]

• Sirolimus (mTOR inhibitor) modulates overactive T-cell signaling and is highly effective in ALPS, producing durable remissions in more than 80 percent of patients.[23,24] Side effects include mouth sores, edema and elevated cholesterol, requiring periodic lab checks.

• Conventional immunosuppressants such as mycophenolate, azathioprine, cyclosporine and methotrexate can reduce steroid dependence but increase infection risk; their use is individualized.[25]

Targeted and pathway-specific therapies

The increased identification of monogenic immune dysregulation syndrome has revolutionized management. Instead of broad immunosuppression, therapies can now be tailored to the affected immune pathway (Table 2).

Hematopoietic stem cell transplantation (HSCT)

HSCT is the only curative therapy for certain severe immune-regulation disorders when medical therapy fails or when cytopenias are life-threatening.[29] Modern conditioning regimens have improved survival, but transplant decisions require careful evaluation at specialized centers.

Infection prevention and supportive measures

Because many therapies suppress adaptive immunity, infection prevention is integral:

• IG replacement therapy (IVIG or subcutaneous IG) should be optimized in all patients with antibody deficiency or rituximab exposure.

• Antimicrobial prophylaxis (trimethoprim-sulfamethoxazole, azithromycin or antifungals) may be used in patients with severe neutropenia, history of severe infections or those taking immune-suppressing medications.

• Vaccinations. Most inactivated vaccines are safe, but live vaccines should be avoided in most PIs and after rituximab or JAK inhibitors.

Table 2. Tailored Therapies Affecting AIC Immune Pathways

Genetic Defect	Pathway Dysregulated	Targeted Therapy	Reported Benefit
4 haploinsufficiency/LRBA deficiency	Impaired T-cell inhibition	Abatacept (CTLA4–Ig fusion)	Improves cytopenias, lymphoproliferation and GI/lung inflammation[26]
1 or STAT3 gain-of-function	Overactive JAK–STAT	JAK inhibitors (ruxolitinib, baricitinib)	Reduces autoimmune cytopenias and systemic inflammation[27]
PIK3CD/PIK3R1 (APDS)	PI3Kδ pathway overactivation	Leniolisib (PI3Kδ inhibitor)	Decreases lymph node enlargement and autoimmune cytopenias[28]
FOXP3 (IPEX syndrome)	T-regulatory cells deficiency	Sirolimus or HSCT	Restores immune balance and improves cytopenias[23]

• Bone health monitoring (vitamin D, DEXA scans) is warranted in those receiving chronic steroids.[30]

When to consider splenectomy

Splenectomy, surgical removal of the spleen, was once a mainstay treatment for ITP, but is now rarely recommended in PI-associated cytopenias due to lifelong infection risk with encapsulated bacteria and often incomplete or transient response.[11] It may be considered only in highly selected refractory cases after failure of medical therapy, with robust vaccination and antibiotic prophylaxis.

Research and Future Directions

Ongoing research aims to improve mechanistic understanding and identify biomarkers predicting relapse or treatment response. Key areas include:

1) Immune profiling: Single-cell sequencing is helping map the immune cell subsets that drive cytopenias in PI.[31]

2) Predictive biomarkers: Cytokine and transcriptional signatures are being explored to forecast relapse and guide therapy.

3) Next-generation therapies: Agents such as BTK inhibitors, SYK inhibitors and regulatory T cell or gene-targeted therapies are under study.

4) Collaborative registries: International databases now track outcomes of PI-related AICs to refine real-world treatment algorithms.[32]

As genetic testing and targeted therapy expand, the management of AICs is shifting from broad immune suppression toward mechanism-based, immune-restorative strategies.

An Important Early Indicator

AICs represent a significant cause of morbidity among patients with PI. They often serve as the first clue to underlying immune dysregulation, and their recognition can prompt earlier diagnosis of inborn errors of immunity. Management requires an integrated, stepwise approach — beginning with corticosteroids and IVIG, progressing to targeted biologic or small-molecule therapies when indicated and incorporating genetic information to guide individualized care.

With the expansion of precision immunology, treatment of AICs in PI is shifting from generalized immunosuppression toward mechanism-based, immune-restorative strategies that not only control cytopenias but also address the fundamental immune imbalance at their root.

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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:

- 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.

PP-CQG-USA-0561

March 2023

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

CONSUMER BRIEF SUMMARY

(CUTAQUIG: *cute-ah-quig*)

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

What is CUTAQUIG?

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

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

WARNING: THROMBOSIS

See full Prescribing Information for complete BOXED WARNING

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

Who should NOT use CUTAQUIG?

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

Tell your healthcare provider if you:

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

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

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- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain
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- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot
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- 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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Profile: Katherine A. Taylor

By Trudie Mitschang

AN ACCOMPLISHED children's mural artist, illustrator, author and art instructor, Katherine Taylor's vibrant, cheerful murals and paintings are featured throughout California. A Southern California native who has overcome the challenges of living with multiple chronic illnesses, Katherine's artistic mission is to create artwork that evokes spontaneous smiles from viewers and makes the world a happier place.

Trudie: How did your journey as an artist begin?

Katherine: I came to art a little later in life. I was in my late 20s, going through a difficult divorce and struggling with an undiagnosed chronic illness that caused constant infections and fatigue. I couldn't sleep at night, so I started painting to keep myself sane. At the time, it was pure therapy — just me, a brush and some paint at two in the morning. But something happened during those sleepless nights. I discovered that creating bright, happy images lifted my spirit, even when my body felt terrible. It became my lifeline.

Trudie: You've said your goal as an artist is to "spark spontaneous smiles." Tell us more about that.

Katherine: When you're living with illness, you start to notice how your environment affects you. I spent years sitting in doctor offices staring at drab landscapes or sterile white walls, and it always made me feel worse. But once in a while, I'd walk into a waiting room that had something cheerful — bright colors, playful images — and I could feel my mood lift immediately. That's when I realized my purpose: to create artwork that makes people feel lighter, even for a moment. My murals are intentionally bold and whimsical because I want them to heal the spirit.

Trudie: When did you finally get an accurate medical diagnosis?

Katherine: It took decades. I had chronic bronchitis, rashes and recurring infections from my 20s onward. I saw more than 30 specialists before an autoimmune dermatologist referred me to an immunologist. At 40, I was diagnosed with common variable immune deficiency (CVID). At first, I started monthly intravenous immune globulin (IG) infusions, and three months later, I switched to subcutaneous IG (SCIG) infusions; it changed my life. I still deal with autoimmune complications, but I'm stronger, more stable and I haven't had a serious infection in years.

Trudie: How did living with CVID shape your outlook on life and work?

Katherine: When you face a chronic illness, you learn that worry doesn't help. If I focused on fear — on all the "what ifs" — I'd make myself sick. I chose joy instead. I live in the moment, create happy art and surround myself with people and animals who make me laugh. That mindset keeps me healthy.

Trudie: What was your first big break as an artist?

Katherine: The Children's Hospital of Orange County (CHOC) decorated its intensive care unit family apartment kitchen with four big prints of my paintings of frogs. CHOC also asked me to paint murals for two of its off-campus clinics and featured my work in its walk-in clinic and family resource room. My prints in the ICU were there for years. The family of a child who survived cancer purchased those same prints for her bedroom. That inspired me to send one of the original paintings to a friend who was awaiting an organ transplant. When she received the painting, she hung it in her room and called it her "Healing Frog." That's when I realized the purpose of my work is to create spontaneous smiles from the viewer and make the world happier.

Trudie: You're also known for your large-scale chalk murals. What draws you to that medium?

Katherine: I love participating in chalk festivals; they are pure joy. I get to work outdoors, side by side with other gifted artists, creating enormous, colorful images. You also meet hundreds of kind people who attend the festivals and stop and smile. I am known for creating *big* silly characters with expressive eyes.

They remind people to play, to laugh, to be in the moment. When you are chalking, you are moving your body and exercising all day because you are getting up and down from the ground. You also work on a tight time frame; you usually have only 16 hours, and the pieces are gigantic — up to 10 feet by 10 feet, so your adrenaline kicks in. The chalk community of artists is super kind as well. It is just an amazing experience.

Trudie: Where can people see your work?

Katherine: I have murals all over Orange County, and I painted two electrical boxes in Santa Maria, Calif. My easiest mural to find is in the city of Brea. I painted a big five foot frog and his family for a bus stop on the corner of E. Birch Street and Associated. One of my electrical boxes in Santa Maria is right in front of the historic Santa Maria Inn. I also have paintings in the walk-in clinic at CHOC and at Pillars Academy, Lucille Packard Children's Hospital at Stanford and multiple community health centers.

Trudie: What inspires you and keeps you motivated?

Katherine: I am motivated by purpose. Even when I am exhausted, I keep painting and chalking. For years, I held a full-time job and spent my evenings painting and teaching art classes. Over time, I built a small business creating murals and teaching art to children. I've taught hundreds of students to draw and paint, and they've taught me just as much about resilience and joy.

Trudie: What does daily life look like for you now, balancing art and chronic illness?

Katherine: Right now, I teach 14 art classes a week, and once a month, I try to participate in a chalk festival or community art project. On Friday nights, I do my SCIG infusion at home. It is a slow infusion that takes over six hours. During my infusion, I practice drawing on my iPad.

Trudie: Tell us about what you've called your second chapter.

Katherine: After years of working, focusing on my health and art, I met my husband when I was 48. He's kind, funny and incredibly supportive. I also adopted two rescue dogs who bring me endless joy. My 20s were difficult years for me, but I am a positive person, and I am living the life I always knew would be possible.

Trudie: You've mentioned your dream is to win a MacArthur Fellowship. What would you do with that opportunity?

Katherine: Winning a MacArthur is my goal! When I receive a MacArthur grant, I'll stop teaching and dedicate my time to creating happy artwork that I can donate to underserved communities such as free health clinics, children's hospitals, infusion centers and homeless shelters. I'd create healing paintings and murals filled with color, hope and humor. Everyone deserves to see something beautiful when they're facing hard times.

Trudie: You're also an author. Tell us about your book.

Katherine: I wrote and illustrated the *ABC Book of Silly Food*, which I self-published under the name K. Emory Taylor and is available on Amazon. It's an early reader ABC book full of bright, funny food characters designed to make reading fun for kids who struggle with learning to read — just like I did. I'm working on creating a series of *Silly Food* books!

Trudie: How do you hope people feel when they encounter your art?

Katherine: I hope they feel a little spark of happiness. Maybe they smile, maybe they take a deep breath, maybe they remember something silly or sweet. If my art can make one person's day brighter — especially someone who's sitting in a clinic or infusion chair — then I've done my job.

Trudie: What do you want others living with immune disorders to take away from your story?

Katherine: Your diagnosis doesn't define your destiny. You can still chase your dreams; you just might have to do it differently. Become your own advocate, listen to your body, celebrate the beauty of the world, and find something that lights you up. Be grateful for amazing doctors, medical treatments and kind people. Our world is beautiful, and sometimes you need to search for small miracles like blooming flowers, sunsets, listening to waves roll on a beach, music. You're stronger than you think. Find what you love, even if it's small, and let it pull you forward. Surround yourself with people who lift you up. When life feels heavy, create something, write, sing, plant a flower — because creativity and kindness are things you can never run out of. Also, visit a chalk festival; you'll be amazed at the murals that are evolving around you. Look for me and say "hello." I am easy to find. I'll be wearing a giant cowboy hat, and I'll probably be drawing a giant weenie dog or a little girl giraffe with bows on her horns. IG

Editor's note: To learn more about Katherine and find a list of her upcoming festivals, visit her website at www.poetryfrog.com and follow her on Instagram @poetry_frog.

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

Celebrating the Small Stuff

By Megan Ryan

I WAS born an achiever, a natural striver. Once I accomplished one thing, I moved on to the next thing without looking back. In my 1980s elementary school days, it was mastering each color-coded level of the SRA Reading Laboratory boxes. Yes, I know some of you will remember those boxes! Or memorizing fourth-grade Texas history trivia, such as all the rivers in the state, to earn extra credit points. Later, in college, it was earning top grades on projects and exams and successfully completing each course in my degree plan. Yes, I celebrated the big achievements, like college graduation, but it has taken me nearly 50 years and some lived experience to realize life is also about celebrating the little stuff.

Celebrating small achievements — and you get to define what "small" and "achievement" mean — has been important for my mental health. When I acknowledge smaller wins, I create a positive pattern that keeps me motivated over time. Each small celebration gives me a little boost that builds momentum and makes me want to keep going. Without these regular doses of encouragement, it's easy to get discouraged and give up entirely.

Recognizing small achievements has also helped me fight my perfectionist tendencies. When I only celebrated major milestones, I was basically telling myself that my daily efforts didn't matter, which left me feeling inadequate. Now, I try to appreciate the process rather than being focused only on distant outcomes.

I'm not a world-class chef or award-winning baker, but over the years, I've learned the skills to navigate my home kitchen and create nutritious meals and

celebration-worthy desserts. Did I begin my journey in the kitchen with Beef Wellington? No. I started with some basics: the family classics. Then I moved on to duplicating restaurant favorites. Was every recipe a success? No. Were some meals eaten once and never again? Yes. Did some take a regular spot in the family meal rotation? Absolutely! It's all because I tried new things, moved on, laughed at some less-than-stellar meals and celebrated my accomplishments. Each kitchen success gave me a little boost of satisfaction, and I got the joy of seeing my family and friends enjoy a meal or a delectable dessert that I made.

Celebrating small wins builds confidence in your ability to achieve things — in the kitchen, in the gym, in the classroom or wherever you want to grow. Feeling capable is so important because it affects how you approach challenges and setbacks. When you believe in your ability to handle what comes your way, you're more likely to try new things and bounce back when something doesn't work out.

Acknowledging small wins also helps me maintain perspective during difficult periods. When I'm going through tough times, being able to point to small positive steps I've taken gives me hope and prevents me from feeling completely stuck or worthless. Sometimes, on really hard days, my small win might be as simple as getting out of bed, taking a shower, or making one phone call I'd been putting off. And that's OK. Those things count too.

This practice has also helped me feel more grateful and present. Instead of constantly looking ahead to what I haven't accomplished yet, celebrating small achievements grounds me in what I'm actually doing well right now.

So how can you practically celebrate the small stuff? One of my favorite authors and podcasters, Gretchen Rubin, encourages her readers and listeners to make a "ta-da" list instead of always thinking about a to-do list. To-do lists can often feel overwhelming or discouraging, though they're often necessary. But equally necessary are moments to revel in what we have accomplished, even the small stuff. We gain energy to keep going, but it's also rewarding to pause and reflect on the progress we've made.

So now it's time to get out some paper and a pen and write your "ta-da" list. What little accomplishments of the day, week, month or year are you proud of? Now sit down and share that "ta-da" list with a friend, even a furry friend, who will listen attentively and cheer, purr or wag you on!

MEGAN RYAN is a native Texan, lover of flowers, plants and gardening and always planning for an upcoming travel adventure. For more than 22 years, Megan has lived with common variable immune deficiency. She's taken her weekly treatments on the road to more than 20 countries and four continents so far.

The Courage to Say Yes to Change

By Michelle Searle

LAST FALL, I was living and working in Lisbon, Portugal, as a coordinator with Northeastern University. In that role, I supported first-year Northeastern students studying abroad for their first semester of college. I helped them navigate cultural adjustment, academic expectations and personal challenges, enabling them to make the most of their international experience and settle into life in Lisbon. Prior to that, I spent most of my summer in Florida, helping to care for my mom as she faced some health challenges and spending time with family before going to Lisbon. I was juggling doctor visits (hers this time), trying to see as many family members and friends as possible, squeezing in moments of rest by the pool and preparing mentally and logistically for what would be one of the biggest professional leaps I've taken since being diagnosed with common variable immunodeficiency (CVID): transitioning from a career in teaching to the field of international education with this job taking me abroad for four months. I didn't even know where I would be placed when I applied and accepted this role. I just knew it would be in one of seven European countries.

This career change has been a long time in the making. Over the past couple of years, I've been working toward transitioning from elementary education into international education, as I realized that this is truly where my passion lies. I love supporting students as they navigate new cultures, build independence and grow in ways they never expected. Having CVID didn't drive my decision to change careers, but I'll admit I'm breathing a sigh of relief. After working in classrooms full of young kids, especially during cold and flu season in a cold climate like New York, it's a welcome change not to be constantly surrounded by germs or wearing a mask every day at work. When I lived and worked in Florida, I didn't think much about cold and flu season. But in New York, it feels never-ending. This new role feels like a better fit for my career, my goals and my body.

Before boarding my flight to Boston in August for two weeks of job training, I wasn't sure how I was going to do it all. Not just physically but emotionally, too. How do you step into something exciting and unfamiliar when you're also carrying the unpredictability of a chronic illness? I didn't have all the answers, but I said yes anyway because I had done it before, when I went away to college and when I moved to Italy after graduating.

Taking this new job wasn't my first leap, and I knew it wouldn't be my last. But that didn't mean it was easy. Living with CVID means every opportunity, no matter how exciting, comes with a long list of questions: What if I get sick abroad? Will I be able to get the medication I need? What if I don't have the energy to keep up? How do I advocate for myself in a brand-new job and a brand-new country? I've asked versions of these questions many times before, and honestly, they never fully go away. But over the years, I've learned that waiting until everything feels certain means waiting forever. So, instead of waiting, I plan. I prepare. I build in support where I can. And I remind myself that I'm allowed to want more than just stability. I'm allowed to want and have adventure, growth and change, too.

Of course, saying yes didn't mean going in mindlessly. I did what I always do before a big transition: I made sure I had the medication I needed, developed a plan ahead of time for what I would do if I got sick, and informed my immunologist of this change. He gave me some antibiotics to take to Portugal in case I got sick. I've also been trying to plan my infusions around my schedule so that if a migraine hit, it would hopefully fall on a day off. I also reminded myself that preparation doesn't eliminate uncertainty; it just helps you meet it with a little more confidence. There's never a guarantee that things will go smoothly, but I've learned I don't need complete certainty to move forward. I just need enough support and enough trust in myself to take the next step.

As I reflect on the past few months in Lisbon, I'm reminded why I said yes in the first place: to grow, to challenge myself and to keep living fully with CVID. There, of course, have been highs and lows, but I'm proud of myself for showing up. Once I return to the U.S. this winter, I hope to share more about this experience and what it has taught me.

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.

Managing the Mental Load of Parenting a Rare Child

By Jessica Leigh Johnson

WHEN PEOPLE hear the phrase "the mental load of parenting," they often think of a never-ending list of tasks and responsibilities such as meal prep, bathing, play dates, birthday parties, dentist appointments, school fundraisers — the list goes on and on. For parents of children with a rare or chronic condition, that list expands into something far more mentally taxing and complex: insurance referrals, specialist visits, refills, symptom tracking and the emotional toll of trying to make life as normal as possible for these children when it's anything but. Parenting a child with a rare or chronic condition requires constant vigilance. It's not just the physical act of driving to the doctor appointments or completing the task of weekly infusions; it's the mental effort required to anticipate needs before they arise. To know when the common viral infection has become pneumonia. To start antibiotics now or wait just one more day to see if symptoms improve.

This extra yet invisible burden is the "mental load" of raising rare children. It goes above and beyond the already heavy responsibility of raising kids. A heavy mental load impacts parents' mental health, physical well-being and their relationships with family and friends. Fortunately, once parents are made aware of the load and how it affects them, there are strategies available to help manage and alleviate some of the pressure.[1]

When the Mental Load Takes a Physical Toll

For most kids, a fever or a cough is just a brief disruption in an otherwise normal childhood. But for chronically ill children, especially those with a primary immunodeficiency (PI), a cough and fever can mean a common cold has turned into something more serious, like a bacterial infection, that may require medical intervention or even hospitalization. Because of this, parents of PI children and other chronic health conditions develop an extreme sensitivity to the slightest change in their children's health status — their activity level, the temperature of their skin, how much they're eating and drinking, the sound of their breathing, etc. This level of hyperawareness becomes second nature, but it comes at a cost to parents' physical health.

The brains of parents who are raising a child with complex needs can become high-speed taskmasters — constantly assessing risk, tracking progress, managing therapy and juggling family, work and household responsibilities. Throw in an unexpected hospital visit, surgery or illness, and things can quickly spiral out of control. The onslaught of adversity can start to seem relentless, and parents may struggle with feelings of guilt and grief, and at times, life can feel completely overwhelming.[2]

Symptoms of Mental Overload

The physical manifestations of mental overload can start subtly, then become more frequent over time. Common symptoms like forgetting names, birthdays, medical appointments, losing keys or misplacing things can easily be blamed on other root causes such as age, hormone status (especially for women) or more severe conditions like dementia. This mental fatigue can be likened to an "induced ADHD or PTSD," although it may actually be one or both of these things, as well.

Chronic stress-induced cognitive dysfunction can happen when the brain is overloaded. It occurs when the brain is forced to adapt to too many changes, too quickly, for too long, and it's incredibly common for long-term caregivers.[2]

Medical research now confirms that chronic stress causes physical changes in the brain. Prolonged exposure to high levels of the stress hormone cortisol actually shrinks the hippocampus, which is the part of the brain responsible for learning and memory. High cortisol exposure also disrupts the function of the prefrontal cortex, which handles decision-making, emotional regulation and attention. Additionally, too much of this hormone overactivates the amygdala, the fear center of our brains, and causes us to be more reactive and feel more anxious.[2]

High stress disrupts hormone production, especially hormones in women such as estrogen and progesterone, which are critical to mental clarity, sleep and emotional stability. According to a 2009 study out of the University of California, San Diego, "mothers of children with autism showed cortisol patterns identical to soldiers in combat zones."[2] They experienced the same hypervigilance and the same activation of fight-or-flight mode — only it never ended.

Managing the Mental Load

These strategies may help reduce the harmful effects of mental overload:

- Acknowledge that the mental load exists.[1] Since you can't see it, it's easy to

dismiss. Acknowledgment helps parents have open, honest conversations about how to share the responsibility more equally.[1]

• Delegate responsibilities evenly. If only one partner feels he or she is constantly thinking ahead and managing the details of their child's care, this can lead to frustration and resentment. Parents need to share the load.[1]

• Set realistic boundaries. Don't feel guilty about saying no to extra responsibilities. Prioritize what matters most, and set limits to protect your mental space and ensure you're not taking on more than you can handle.[1]

• Take time for yourself. Many parents neglect to take time for themselves amid the responsibilities of caring for their child. However, planning personal time is critical for reducing stress. Carve out time for yourself to recharge your mental energy.[1]

• Use shared calendars. Apps like Google Calendar allow you to create events, set reminders and share important dates, such as doctor visits, which help you be clear about responsibilities that seem to go unnoticed.[1] By openly discussing responsibilities, less-involved partners become more aware of the mental work required to raise their rare child.

• Practice mindfulness meditation. This involves paying attention to the present. Simple mindfulness exercises such as deep breathing and silent reflection help to calm the mind and reduce stress. Meditation apps like Headspace or Calm can help.[1]

• Journal to unload thoughts. The act of writing down thoughts, concerns or to-do lists helps you clear your mind and make space to focus on what matters most.[1] Reading the journal entries at the end of the week can give you a clearer picture of the cognitive work involved in parenting your rare child and can be a real eye-opener.

• Seek therapy and counseling. When the mental load starts to feel overwhelming, it may be time to seek professional help. A licensed therapist can help you develop coping strategies to manage stress, anxiety and overwhelm,[1] and provides a safe space to talk about the emotional and mental toll of parenting a child with a chronic condition.

• Join parenting support groups. Whether in person or online, support groups offer a sense of community and connection for people with shared experiences. Talking with other parents dealing with similar challenges can provide practical advice and reassurance and a sense that you're not alone.[1]

After parenting three boys with XLA and losing a fourth at the age of 9 months to complications of undiagnosed XLA, I have suffered with anxiety and PTSD for years, completely unaware of how much my children's condition was affecting me. Every cough was triggering. My oldest son has bronchiectasis and a chronic cough, so every time one of the younger boys would cough, especially at night, I would go into fight-or-flight mode. My heart would race, my pulse would pound in my ears and it would feel like adrenaline was coursing through my veins. At that point, sleep was impossible. News stories of viral outbreaks like COVID-19 and H1N1 were also extremely triggering, since my middle son died from adenovirus infection.

I had no idea I had PTSD until I was diagnosed with breast cancer in 2022 and finally sought treatment after my mental health began spiraling. I started seeing a therapist and eventually gave in to the idea of trying an anti-anxiety medication. It has helped tremendously. The high levels of cortisol that come from constantly being "on alert" (fight or flight) were harming my body and causing my heart to beat abnormally. Anti-anxiety medication calmed this response, and my heart went back to normal. In the long run, this routine of therapy and medication will be beneficial to my heart and overall physical health. I share this story simply to help encourage other parents who may find that the years of parenting a child with a chronic illness have taken too much of a toll on their well-being. You may not even know you've been living this way, but if any of this sounds familiar and describes you, it's OK to seek help.

Managing the mental load of parenting a rare child is a continuous process, but with the right tools and strategies in place, you can find balance and peace. Remember, your mental health and well-being are as important as your child's physical health.[1] IG

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1. Valencia, AM. Manage the Mental Load of Parenthood: Here Are 8 Strategies for Better Health. Omega Pediatrics, Dec. 12, 2024. Accessed at www.omegapediatrics.com/strategiesmanage-mental-load-of-parenthood.
2. Conn, L. Navigating the Mental Load of Parenting a Child with Additional Needs. NAPA, July 22, 2025. Accessed at napacentre.com.au/parenting-a-child-with-additional-needs.

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Gluten-Free Eating

By Rachel Maier, MS

STICKING TO a gluten-free diet is a lot easier today than it was even 10 years ago. I know, because I've been eating a gluten-free diet for that long, and things today are better than they were back then. Significant improvements in selection, taste, quality and availability of gluten-free alternatives makes eating these foods enjoyable and accessible. It's even getting easier to eat out at restaurants! But *easier* doesn't mean *easy* — finding gluten-free foods, whether at home or on the go, is still a lot of work.

First, Understand Labels

The United States Food and Drug Administration (FDA) requires that any food containing wheat must include that information on the product label.[1] However, wheat is not the only source of gluten. Also, the gluten-free label is a voluntary claim food manufacturers can make about their product if it meets FDA requirements (the food contains less than 20 parts per million [ppm] of gluten,[2] among other things) for the gluten-free claim.

What about products claiming to be certified gluten free? The Gluten-Free Certification Organization (GFCO) works to ensure that gluten-free products are labeled appropriately and safe for consumers to eat. To qualify for GFCO certification, the food must test at least 10 ppm or lower. The GFCO certification is meant to help consumers eat gluten-free foods with confidence. (Look for the certified gluten-free logo.)

Spend Selectively

Specialty grocery stores are amazing because they are stocked with all kinds of super-fun gluten-free products. However, you do not need to shop exclusively at these high-end grocery stores. They are expensive, and stocking up on high-priced specialty convenience foods will drain your wallet fast. Go to those stores for items you know you need (such as gluten-free puff pastry). Allow yourself to pick up one splurgy item (such as a box of gluten-free donuts), and stick to your local supermarket for the bulk of your food. Another option? Look for your favorite gluten-free items in big box stores such as Target and Walmart, or order in bulk online.

Don't forget: Most of the healthiest, whole foods you can eat are naturally gluten free and are available pretty much anywhere. Fresh cuts of chicken, beef and pork; fresh or frozen fish fillets; eggs; and every fruit and vegetable at your local grocery store are 100 percent gluten free. Dairy products are generally gluten free (think milk, yogurt, cheese, etc.). Many whole grains are gluten free as well (such as rice, quinoa, corn) as are beans. Yes, cooking from home involves planning and effort, but it is healthier and more affordable for everyone — whether they must eat a gluten-free diet or not.

There's an App for That!

Eating at home isn't always an option, but eating away from home is hard! Thankfully, there are all kinds of apps to help you make informed choices. Apps such as Fig, Gluten Free Scanner and Gluten Free for Me allow you to scan the barcode of food products to help you determine whether or not it is truly gluten free. Apps such as Find Me Gluten Free, Gluten Dude and Spokin guide you toward eateries near you that offer gluten free menu items.

Use What Makes Life Easier

Even after a decade of eating exclusively gluten free, I am still learning how to cope. Some days it's really easy to eat gluten free, and some days it's really difficult. Because of that, I give myself grace and rely on things that make life a little bit easier. See the shopping guide for some of my favorites.

References

1. United States Food and Drug Administration. Food Allergies. Accessed at www.fda.gov/food/nutrition-food-labeling-and-critical-foods/food-allergies.
2. United States Food and Drug Administration. Gluten and Food Labeling. Accessed at www.fda.gov/food/nutrition-education-resources-materials/gluten-and-food-labeling.

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

The Celiac App

Created by celiacs for celiacs, this free app is the best place to get accurate answers about gluten-free questions when and where you need them. It features CeliaChat, an in-app assistant trained by celiac experts to answer your questions; a myths vs. facts feature to clear up common misconceptions; a product database with up-to-date lists of the best gluten-free foods; gluten-free menus; a gluten-free dining guide with menus from 28 chain restaurants and 19 cuisine guides; translation cards for seamless communication; and more! This app is designed to give you confidence for eating out again.
$7.99/month; www.theceliacspace.com/tca

Taste Republic Fresh Pasta

If the thought of another gluten-free pasta makes you cringe, you haven't tried Taste Republic. This fresh pasta is certified gluten free and made on dedicated gluten free equipment — and it tastes like the real deal: authentic fresh pasta. (It holds up like it, too!) Yes, it's a splurge, but it's one that will not disappoint. Packages can be ordered directly from the website, or you can use the store locator to find it at a retailer near you (single package prices may vary).
$59.99 for a variety pack of six; tasterepublic.com/collections/gluten-free-pasta/products/fresh-gluten-free-pasta-variety-pack-6-pack

Shopping Guide for Gluten-Free Eating

Namaste Foods Gluten Free Baking Mixes

Gluten-free baking is tricky, but these boxed mixes make it easy to bake with confidence. A grass-roots gluten-free company, Namaste Foods started small, using the finest ingredients and the best manufacturing methods to honor those with special diets with safe, delicious and affordable foods. From cake and cookie to muffin and scone mixes, every product is free of the top nine allergens, gluten free and made in a dedicated gluten-free facility.
Start at $5.59; namastefoods.com/collections/gluten-free-baking-mixes-and-flour

San-J Tamari

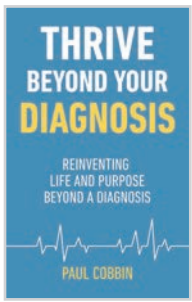
Most ordinary soy sauce contains wheat, but San-J tamari sauce is anything but ordinary. In fact, this soy sauce — tamari — is brewed without wheat, making it gluten free and safe for people with a wheat allergy. San-J also makes Asian cooking sauces such as Teriyaki, Szechuan, Hoisin and — my favorite — orange chicken sauce. San-J even makes gluten-free white miso soup mix! San-J makes quick, authentic-tasting Asian cuisine a possibility for those who must avoid gluten. *$9.99; san-j.com/tamari-soy-sauce*

My Dad's Cookies

These delicate cookies are as pretty as they are delicious. Founded by a father whose daughter was diagnosed with celiac disease when she was 10 years old, My Dad's Cookies prove gluten-free eating doesn't have to compromise on flavor. The dainty cookies are sold separately or as a variety pack (pictured here). They accommodate gluten-free, dairy-free and nut-free diets so that no one has to feel left out when it comes to enjoying a treat.
Start at $6.95; www.mydadscookies.com/collections/cookies

Sweet Loren's Puff Pastry

From the gluten-free ready-made cookie dough company you know and love comes a revolutionary new staple in your gluten-free kitchen: ready made puff pastry dough! This dough bakes up puffed and perfectly golden — proving gluten-free food can be every bit as delicious as the foods you remember.
$8.99; www.target.com/b/sweet-loren-s/-/N-ao79q



Thrive Beyond Your Diagnosis: Reinventing Life and Purpose Beyond a Diagnosis (Decode, Align & Thrive with Chronic Illness Book 3)

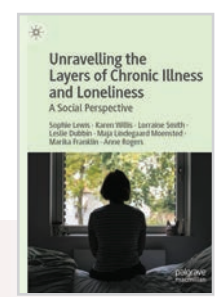
Author: Paul Cobbin
Publisher: Formula For Life Publishing

This is the final stage in Paul Cobbin's acclaimed *Decode Your Diagnosis* trilogy, guiding readers from recovery into renewal. Drawing from his own experiences with prostate and cardiovascular disease, Cobbin offers a grounded, forward-looking framework for lasting well-being and fulfillment. Readers will learn how to turn setbacks into new sources of strength and contribution; apply the Rings of Resilience to sustain health, relationships and work; design routines and environments that protect their energy and creativity; and transform their story from "survivor" to Titan as someone thriving with clarity and agency.

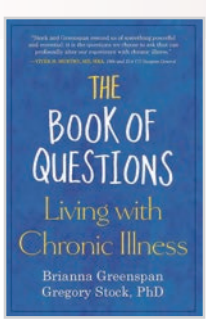
Unravelling the Layers of Chronic Illness and Loneliness: A Social Perspective

Authors: Sophie Lewis, Karen Willis, Lorraine Smith, Leslie Dubbin, Maja Lindegaard Moensted, Marika Franklin and Anne Rogers
Publisher: Palgrave Macmillan

This book details the complex and often-overlooked relationship between loneliness and chronic illness. The authors take a social perspective to show how loneliness is shaped by illness experience, life histories and broader social factors such as stigma, social networks, healthcare systems and social inequalities. Drawing on qualitative interviews and the voices of people with chronic illness and those who care for and support them, the chapters in this book show how loneliness unfolds across everyday lives, relationships and places.



New and Useful Reading



The Book of Questions: Living with Chronic Illness

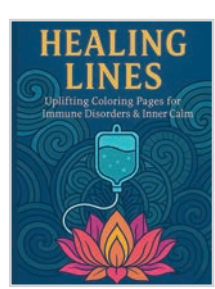
Authors: Brianna Greenspan and Gregory Stock
Publisher: Nquire Media

As the newest addition to the iconic *Book of Questions* series, this book is an invitation for readers to see and hear themselves — perhaps for the first time. The authors explore questions such as "When have you shown great courage and grit in overcoming something most people take for granted?" "Did you celebrate your triumph as much as it deserved?" "What stories do you tell yourself about your illness, and what purposes do they serve for you?" and "Are there other stories that might better serve you?"

Healing Lines: Uplifting Coloring Pages for Immune Disorders & Inner Calm

Author: Dr. Jeffrey Bone
Publisher: Independently Published

Healing Lines was created to bring calm, strength and hope to the journey of living with an immune disorder. This unique coloring book combines soothing artwork with empowering quotes designed specifically for those coping with navigating fatigue, treatments, infusions and moments of uncertainty. Included are 30-plus detailed coloring pages designed for relaxation. The 8.5-by-11-inch single-sided page design makes it perfect for markers, colored pencils or gel pens.



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Ataxia Telangiectasia (A-T)

Websites

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

Chronic Inflammatory Demyelinating-Polyneuropathy (CIDP)

Websites

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

Evans Syndrome

Online Peer Support

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

Guillain-Barré Syndrome (GBS)

Websites

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

Online Peer Support

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

Immune Thrombocytopenia (ITP)

Websites

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

Kawasaki Disease

Websites

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

Mitochondrial Disease

Websites

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

Multifocal Motor Neuropathy (MMN)

Websites

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

Multiple Sclerosis (MS)

Websites

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

Online Peer Support

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

Myasthenia Gravis (MG)

Websites and Chat Rooms

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

Online Peer Support

- Genetic Alliance: www.geneticalliance.org

Myositis

Websites

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

Online Peer Support

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

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)

Websites

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

Pemphigus and Pemphigoid

Websites

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

Peripheral Neuropathy (PN)

Websites

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

Primary Immune Deficiency Disease (PI)

Websites

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

Online Peer Support

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

Scleroderma

Websites

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

Online Peer Support

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

Stiff Person Syndrome (SPS)

Websites

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

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