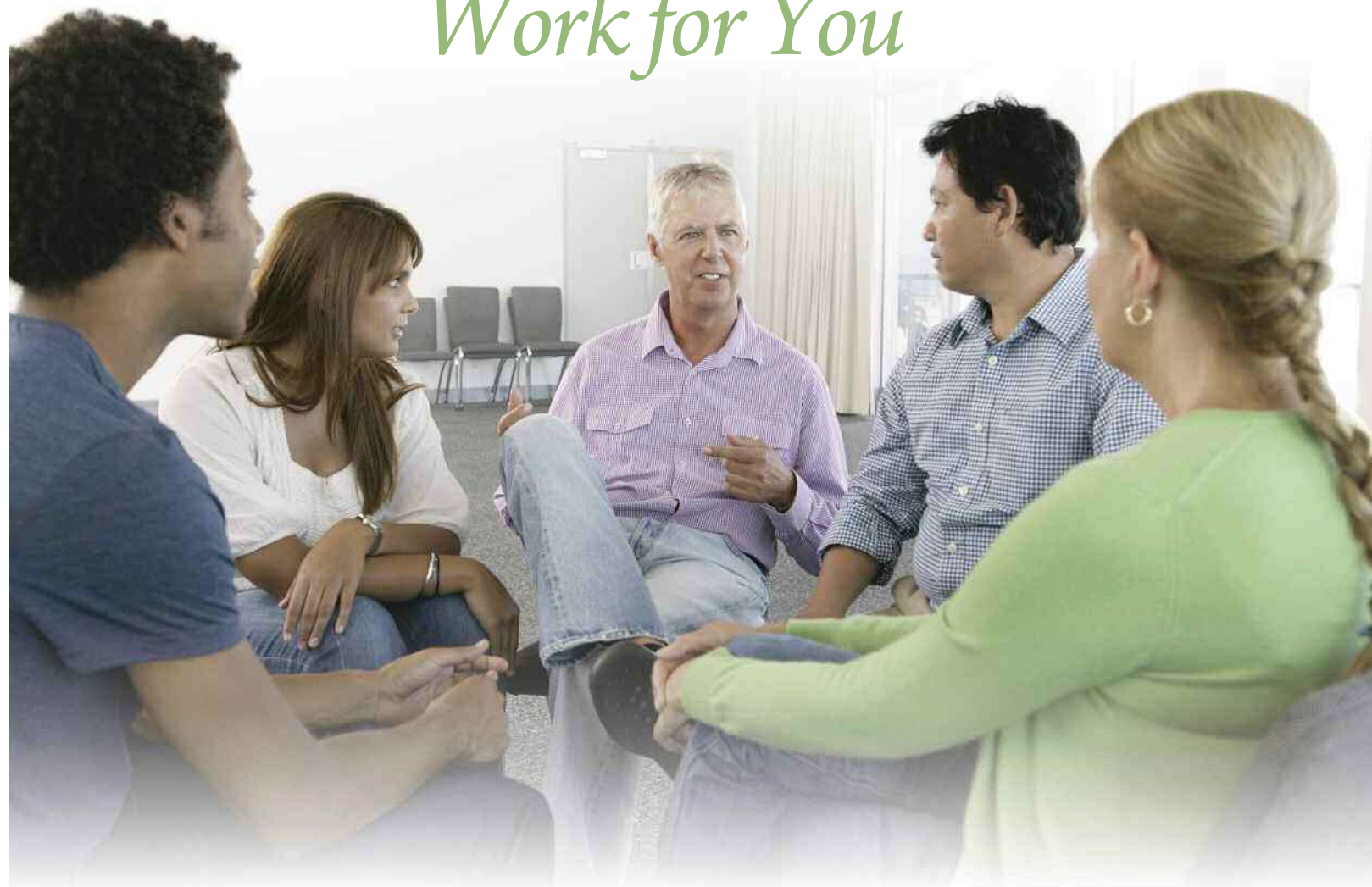


# Making Support Groups Work for You



Patients can use these eight tips to ensure a support group is the right fit for them.

By Dana Henry

**PATIENTS ARE** often interested in joining a support group but don't know where to start. Or, some may have had a bad experience in a support group and feel nervous about trying again. These eight tips can help patients navigate the process of finding the right group for them.

## 1. Learn where to find reputable support groups.

Finding the right group is sometimes more complicated than doing an Internet search. By digging deeper, patients can find a greater variety of groups. Susan Rieger, a licensed clinical social worker who facilitates and participates in several support groups in the Kansas City area, suggests contacting local hospitals to find groups associated with their complementary medicine programs. Patients can also contact nonprofit organizations that support people living with their medical condition. Their staff can help locate support groups in different areas. The Mayo Clinic recommends contacting local resources such as libraries, community centers and places of worship.<sup>1</sup>

## 2. Know what to expect.

When looking for support groups, patients can get a sense of a group's focus and format from descriptions in newsletters or online. Every group should provide guidelines for participation. That document should be available at meetings and will most likely be read aloud before each meeting starts. These guidelines help make the group a safe space for everyone who attends and provide a basis for speaking up if the group seems to be veering from shared expectations.

By definition, support groups deal with difficult subject matter and situations. The skills and background of the group facilitator are essential when strong dynamics arise in a group, Rieger says. To help evaluate the facilitator's experience and philosophy, she suggests calling him or her ahead of time. Patients can use that call to ask the facilitator about his or her leadership strategies and about the group's size and dynamics. Rieger's own philosophy about facilitating groups is that creating a safe space is even more important than providing information.

## 3. Try out different types of groups.

When people think of support groups, the image of a large, sterile room usually comes to mind, one where people sit in a circle taking turns talking about their problems. Though this model certainly exists, support isn't limited to this approach. One alternative is structured educational groups that focus on a topic and are led by a subject-matter expert. Another alternative is groups that have an activity at their core such as groups focused on recreation and creativity.

Rieger, who is a professional dancer, loves to include movement in her groups because, aside from the health benefits of staying active, movement connects all aspects of who we are: physical, emotional, spiritual and intellectual. In cities around the country, there are support groups that incorporate all kinds of activities, from knitting to writing to yoga. So if the more traditional talk-driven groups aren't a patient's first choice, there are myriad ways to find support and connect with others.

## 4. Take advantage of what makes support groups unique.

Support groups provide a space that is unlike any other point of contact in the healthcare system. Unlike the one-on-one relationship patients have with care providers, where there is no reference for what they are feeling other than themselves, the support group allows patients to share their experiences with

others who are going through something similar, as well as learn from those who have been there. This dynamic can be extremely therapeutic.

"It does so much good for comforting people about the things that they think are unusual or specific to them," Rieger says. "There is no one who understands their experience better than someone who has experienced it themselves." She adds that there's a normalizing effect when patients learn they are not alone in what they are feeling. Knowing that many people living with chronic health issues feel anxiety about their condition, for example, can go a long way toward alleviating that anxiety — or at least make living with it more manageable.

"What's really helped me about groups is being in a room full of people who have the same issues and discuss those issues openly," says Chris,\* who has participated in support groups since 2015. "From an early age, I've had the idea that talking about my struggles — including my health struggles — was a sign of weakness. Support groups have shown me that's not the case. The strongest people are those who bravely face their challenges every day."

According to the Mayo Clinic, participation in support groups confers several emotional and practical benefits. Emotional benefits include feeling less isolated, gaining a sense of empowerment and improving coping skills. Practical benefits include developing a clearer understanding of what to expect, getting practical advice or information about treatment options, and comparing notes about resources such as doctors and alternative options.<sup>1</sup>

Perhaps the most important benefit of support groups is that they help participants cultivate relationships, many of which last long after the group has stopped meeting. "Support groups offer support in a way that individual therapy never could, in that this group of people could go on to become an ongoing support system for you," Rieger says. She's seen people from her groups exchange contact information and incorporate group participants into their ongoing support system. Those connections can be central to resilience, healing and endurance. For example, Rieger notes that building a support system is a known way to counter depression.

## 5. Make sure the group is emotionally safe.

Above all, support groups need to be emotionally safe for those who attend. They need to be spaces where introverts and extroverts feel they have equal time to talk. They need to be

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\*Last name omitted upon request

**Hizentra**<sup>®</sup>  
Immune Globulin Subcutaneous  
(Human) 20% Liquid

Hizentra is the only subcutaneous Ig treatment with over **70,000 patient-years** of experience<sup>1</sup>

#1 Ig

Prescribed for PI<sup>1</sup>



### Important Safety Information

Hizentra treats various forms of primary immunodeficiency (PI) in patients age 2 and over.

**WARNING: Thrombosis (blood clotting) 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 thrombosis, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor you for signs of thrombosis and hyperviscosity. Always drink sufficient fluids before administration.**

Tell your doctor if you have had a serious reaction to other immune globulin medicines or have been told you also have a deficiency of the immunoglobulin called IgA, as you might not be able to take Hizentra.

You should not take Hizentra if you know you have hyperprolinemia (too much proline in your blood).

**Infuse Hizentra under your skin *only*; do not inject into a blood vessel.**

Allergic reactions can occur with Hizentra. If your doctor suspects you are having a bad allergic reaction or are going into shock, treatment will be discontinued. Immediately tell your doctor or go to the emergency room if you have signs of such a reaction, including hives, trouble breathing, wheezing, dizziness, or fainting.

Tell your doctor about any side effects that concern you. Immediately report symptoms that could indicate a blood clot, including pain and/or swelling of an arm or leg, with warmth over affected area; discoloration in arm or leg; unexplained shortness of breath; chest pain or discomfort that worsens with deep breathing; unexplained rapid pulse; and numbness or weakness on one side of the body. Your doctor will also monitor

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## PI Support From a Personal Point of View

If you are a Hizentra patient or caregiver, sign up for Voice2Voice to connect with others who have walked in your shoes. Along with offering encouragement and sharing personal experiences, your Voice2Voice advocate can answer non-medical questions\* and connect you to helpful resources.

**We'd love to hear from you.** If you or someone in your care is currently using Hizentra to manage PI and you'd like to share your story, we encourage you to apply to become a Voice2Voice advocate.



Sign up at [voice2voice4pi.com](http://voice2voice4pi.com).

symptoms that could indicate hemolysis (destruction of red blood cells), and other potentially serious reactions that have been seen with Ig treatment, including aseptic meningitis syndrome (brain swelling); kidney problems; and transfusion-related acute lung injury. The most common drug-related adverse reactions in the clinical trial for Hizentra were swelling, pain, redness, heat or itching at the site of injection; headache; back pain; diarrhea; tiredness; cough; rash; itching; nausea and vomiting.

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

Before being treated with Hizentra, inform your doctor if you are pregnant, nursing or plan to become pregnant. Vaccines (such as measles, mumps and rubella) might not work well if you are using Hizentra. Before receiving any vaccine, tell the healthcare professional you are being treated with Hizentra.

**Please see brief summary of full prescribing information for Hizentra on adjacent page. For full prescribing information, including boxed warning and patient product information, please visit [Hizentra.com](http://Hizentra.com).**

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

\*Voice2Voice advocates are not healthcare professionals or medical experts. For medical questions, please contact your physician. Voice2Voice advocates are compensated by CSL Behring LLC for their time and/or expenses.

Reference: 1. Data on File. Available from CSL Behring as DOF HIZ-003.



**Can IgIQ® help you?**  
**If you answer YES to any of these questions,**  
**call 1-877-355-IGIQ (4447) Monday–Friday, 8 AM to 8 PM ET.**

- Have you had a lapse in your insurance coverage?
- Are you unable to afford Hizentra?
- Would you like to connect with other Hizentra patients?
- Do you need help paying for Hizentra?
- Are you unable to afford Hizentra infusion supplies?

Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid  
 Initial U.S. Approval: 2010

**BRIEF SUMMARY OF PRESCRIBING INFORMATION**

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

**WARNING: THROMBOSIS**

*See full prescribing information for complete boxed warning.*

- **Thrombosis may occur with immune globulin products, including Hizentra. 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 Hizentra 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-----

Hizentra is an Immune Globulin Subcutaneous (Human) (IGSC), 20% Liquid indicated for the treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

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

**For subcutaneous infusion only. Do not inject into a blood vessel.**  
 Administer at regular intervals from daily up to every two weeks (biweekly).

**Dosage (2.2)**  
 Before switching to Hizentra, obtain the patient’s serum IgG trough level to guide subsequent dose adjustments.

- **Weekly:** Start Hizentra 1 week after last IGIV infusion  
 Initial weekly dose =  $\frac{\text{Previous IGIV dose (in grams)}}{\text{No. of weeks between IGIV doses}} \times 1.37$
- **Biweekly:** Start Hizentra 1 or 2 weeks after the last IGIV infusion or 1 week after the last weekly Hizentra/IGSC infusion. Administer twice the calculated weekly dose.
- **Frequent dosing (2 to 7 times per week):** Start Hizentra 1 week after the last IGIV or Hizentra/IGSC infusion. Divide the calculated weekly dose by the desired number of times per week.
- **Adjust the dose** based on clinical response and serum IgG trough levels.

**Administration**

- Infusion sites – 1 to 4 injection sites simultaneously, with at least 2 inches between sites.

Infusion Parameters*	Infusion Number			
	1 <sup>st</sup>	2 <sup>nd</sup> to 4 <sup>th</sup>	5 <sup>th</sup>	6 <sup>th</sup> and above
Volume (mL/site)	≤ 15	≤ 20	≤ 25	≤ 25
Rate (mL/hr/site)	15	≤ 25		

\* As tolerated

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

0.2 g per mL (20%) protein solution for subcutaneous injection

-----CONTRAINDICATIONS-----

- Anaphylactic or severe systemic reaction to human immune globulin or components of Hizentra, such as polysorbate 80
- Hyperprolinemia (type I or II) (Hizentra contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

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

- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions.
- Thrombosis may occur following treatment with immune globulin products, including Hizentra.
- Aseptic meningitis syndrome has been reported with IGIV or IGSC treatment.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of acute renal failure.
- Monitor for clinical signs and symptoms of hemolysis.
- Monitor for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI])
- Hizentra is made from human plasma and may contain infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

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

The most common adverse reactions observed in ≥5% of study subjects were local reactions (i.e., swelling, redness, heat, pain, and itching at the injection site), headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, rash, pruritus, vomiting, abdominal pain (upper), migraine, and pain.

**To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch).**

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

The passive transfer of antibodies may interfere with the response to live virus vaccines, and lead to misinterpretation of the results of serological testing.

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

- **Pregnancy:** No human or animal data. Use only if clearly needed.
- **Pediatric:** No specific dose requirements are necessary to achieve the desired serum IgG levels.

spaces in which all information shared is held in confidence. They even need to be safe spaces to not speak if a participant wants to listen but doesn't feel comfortable sharing. If a group doesn't have guidelines, doesn't seem to follow its guidelines or feels unsafe in any other way, patients should trust their instincts and either take steps to improve the group or move on to one that is emotionally safe.

In addition to its guidelines, signs that a group is emotionally safe include participants practicing good listening skills (e.g., making eye contact, not talking while someone is sharing, not checking cell phones), practicing fairness in terms of how much time each person has to speak (e.g., not allowing individuals to dominate the conversation, not allowing extroverts to do most of the talking), honoring confidentiality (e.g., not talking about a participant in his or her absence, not divulging something to the group that a participant shared with only one person) and refraining from giving unwanted advice.

To evaluate emotional safety, Rieger encourages participants to ask themselves several questions. Does it feel like you are being listened to? Is one person dominating? Also, how anxious do you feel in the space? While some anxiety is normal for everyone before attending a support group, especially for the first time, an ongoing high level of anxiety could be an indication that the space isn't safe for a person.

"The last time I attended one of my support groups, I had so much anxiety about what had happened during the meeting that I felt my own health was at risk," Chris says. This was a red flag he couldn't ignore. After careful consideration, he decided not to go back to that particular group. "I didn't know how I could return and preserve my personal health and well-being."

Other red flags include the following:<sup>1</sup>

- Groups that promise a cure for your condition
- Meetings that are largely focused on complaining
- Facilitators or participants who urge you to stop your medical treatment
- Participants who are disruptive or who judge your decisions or actions
- Pressure to purchase products or services
- High attendance fees

If patients find themselves in a situation that prompts them to leave a group, they should remember that not all groups are created equal. Patients can have a bad experience in one group without giving up on support groups entirely. With some time and effort, they should be able to find another group that will serve them well.

## 6. Remember that you decide what to share.

When patients attend a support group, they need to set their own boundaries. They have the right to share only what they want to share, even if everyone is opening up in deeply personal ways. They have the right to try a group out a few times until they know it's a safe space for them and what role the group can play in their journey. "You are your own monitor," Rieger says. "Other than sharing your [first] name, you get to decide when it's time to talk and how vulnerable to be."

PERHAPS THE MOST  
IMPORTANT BENEFIT OF  
SUPPORT GROUPS IS THAT THEY  
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GROUP HAS STOPPED MEETING.

## 7. Know that seeking support doesn't make you weak.

Getting support doesn't make people weak. It makes them strong — and the experience can make them even stronger. Research has shown that people who take part in support groups have less anxiety, stress, emotional distress, fatigue and pain, as well as improved mood, self-image and feelings of being in control.<sup>2</sup>

## 8. Give it a try.

If patients are still on the fence about attending a support group, Rieger's advice is simple: "Try it one time and see if it feels right." If not, no big loss. But if they enjoy it, they have plenty to gain. ■

**DANA HENRY** is a writer and editor in the Kansas City area who specializes in science, medicine and health.

## References

1. Mayo Clinic. Support Groups: Make Connections, Get Help. Accessed at [www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655](http://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655).
2. John Stoddard Cancer Center. UnityPoint Health, July 25, 2014. Five Powerful Benefits of Joining a Cancer Support Group. Accessed at [www.unitypoint.org/desmoines/article.aspx?id=cccc3999-2b26-40f2-be1e-9e988a3563d3](http://www.unitypoint.org/desmoines/article.aspx?id=cccc3999-2b26-40f2-be1e-9e988a3563d3).