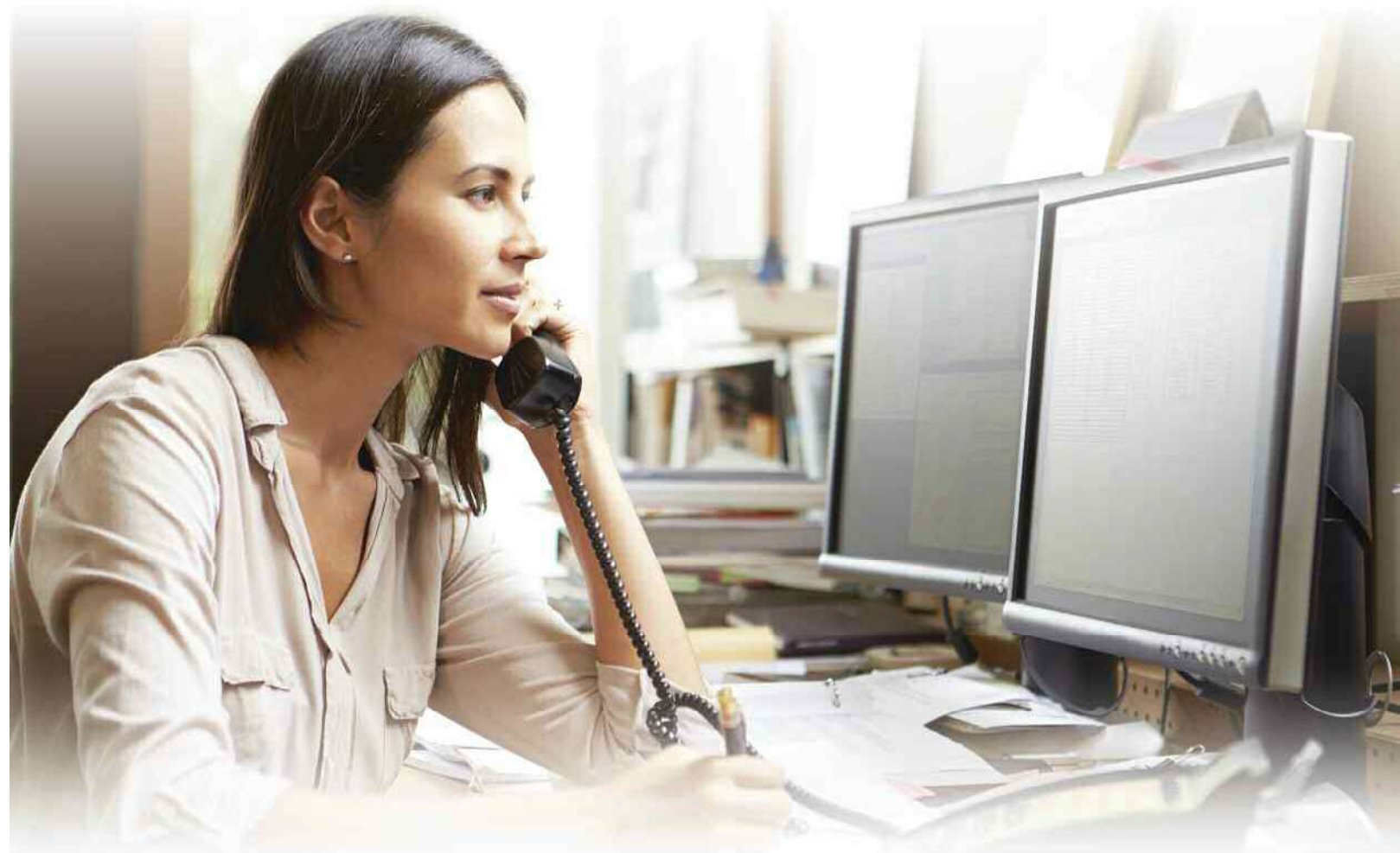


# *Paving the Way for Healing:* **The Role of the Patient Advocate**

By Dana Henry

You've probably heard the saying: "Be your own advocate." But, sometimes, that's easier said than done. Trying to wrangle all aspects of a complicated health issue can leave patients feeling frustrated, discouraged and drained. If that's the case, a patient advocate might be just the ticket.



**FINDING THE RESOURCES** and care one needs to deal with a challenging medical condition can be difficult. It may require getting a second opinion, coordinating with several specialists, having numerous tests or procedures, coordinating follow-up appointments, weighing different treatment options, spending time in the hospital and juggling complex treatment plans. Just reading that list can be a little overwhelming. It's easy to see how actually working through all those steps can become a full-time job and can keep patients from focusing on their health and well-being. And, that's where patient advocates come in. Their role is to assist patients so they can focus on what matters: their health.

## **What Do Patient Advocates Do?**

A patient advocate is someone who can help patients navigate their healthcare journey in myriad ways. Professional patient advocates work with hospitals, insurance companies and drug manufacturers, as well as independently as private patient advocates. Lay advocates don't have formal training but can nonetheless be invaluable. They are often the friends and family members of those living with serious health issues. This article mainly deals with professional patient advocates. (Find tips for working with lay advocates in the sidebar titled "Four Ways to Recruit and Support Lay Advocates.")

The Agency for Healthcare Research and Quality defines a health advocate as someone who can ask questions, record information and speak up for patients so they can better understand their condition and get the care they need.<sup>1</sup> However, an advocate's role can be much wider ranging (Table 1). The National Patient Safety Foundation defines a patient advocate as a "supporter, believer, sponsor, promoter, campaigner, backer or spokesperson."<sup>2</sup> An advocate can also focus on a narrower range of services, such as those who specialize in medical billing.

In the *Journal of Medical Ethics*, Lisa Schwartz writes that an advocate can help patients translate their desires into a cogent treatment plan and can help steer medical teams in the directions patients prefer. But, there are many other reasons for patient advocacy, Schwartz says, adding that there are also caveats, including ensuring the advocate can clearly understand patients' needs and can represent those needs without distortion.<sup>3</sup> The demand for patient advocates is evident. In 2007, CNN listed patient advocacy as one of seven positions poised for growth.<sup>4</sup> In 2010, the Institute for Change Partners in Care Foundation identified patient navigation/advocacy as one of six emerging healthcare occupations that have the potential to keep people healthier and lower healthcare costs.<sup>5</sup>

### Finding a Professional Patient Advocate

There are many reasons patients may want to work with a professional advocate. "Volunteers can be wonderful, and the price may be right, but they often don't have the experience you need to be sure you're getting the best care you can get," says Trisha Torrey, who works as a writer, speaker and private patient advocate.<sup>6</sup> Here are three ways to find different types of advocates.

**Insurance.** Patients who are insured can check their health insurance benefits. Large employers often provide advocate services such as Health Advocate, the nation's biggest employee-based advocacy firm.<sup>7</sup> Some Blue Cross and Blue Shield plans, for example, offer free advocate programs to help patients and their families with complex healthcare issues. Services offered through these programs include obtaining pre-authorizations and prior approvals, speaking to medical staff with a patient or on a patient's behalf, suggesting community resources and resolving billing issues.<sup>8,9</sup>

**Online directories.** Several websites offer directories of private patient advocates. These include AdvoConnection ([advoconnection.com](http://advoconnection.com)) and the National Association of Health Advocacy Consultants ([nahac.memberlodge.com/directory](http://nahac.memberlodge.com/directory)).

Torrey also recommends patients search for phrases such as "health advocate" and "patient advocate," along with the name of the area where they live to find advocates in their vicinity. Many advocates will have websites or LinkedIn profiles so patients can get a sense of the services they offer and the fees they charge.<sup>6</sup>

**Drug manufacturers.** Some manufacturers offer paid and volunteer advocates to support patients in learning about their conditions and using their company's medications for treatment. For instance, CSL Behring and Baxalta, manufacturers of

**Table 1.**  
**Types of Assistance a Patient Advocate May Offer**<sup>6,8,9,12,13</sup>

- Arrange transportation
- Ask questions about next steps with regard to diagnosis and treatment
- Compile or update vitamin, supplement and medicine lists
- Discuss recommended health services
- Explain benefits
- Explain medical jargon
- File paperwork and assist with insurance matters
- Find support groups and other community services
- Get pre-authorizations and prior approvals
- Give the patient and family members emotional support
- Help with delays in getting tests, treatment or information
- Help the patient follow treatment instructions
- Help the patient get copies of relevant medical records
- Locate doctors and specialists
- Make sure the patient and family members know the facts about the patient's condition and care
- Manage physician referrals
- Navigate healthcare networks
- Recommend health and wellness programs
- Research treatment options, procedures, doctors and hospitals
- Resolve hospital and doctor/provider billing issues
- Respond to requests and concerns 24/7 or during set hours
- Schedule appointments

More than 

patients and providers have put their confidence in Hizentra<sup>1</sup>



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ONCE EVERY  
2 WEEKS

**Hizentra—Ig therapy that fits your lifestyle.**

**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.**

**Please see additional Important Safety Information on reverse side and brief summary of full prescribing information for Hizentra, including boxed warning, on adjacent page.**

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



## Complete Support, All in One Place

IgIQ is a resource center for people who depend on the Ig therapies offered by CSL Behring, including Hizentra.

### What can our friendly and knowledgeable IgIQ staff do for you?

- Answer general (non-medical) questions\*
- Provide helpful resources
- Enroll you in peer support and financial assistance programs
- Answer questions related to insurance coverage

\*IgIQ personnel are not medical experts; medical questions will be forwarded to the appropriate CSL Behring department.

For more information, call **1-877-355-IGIQ (4447)** Monday–Friday, 8 AM to 8 PM ET.

#### Important Safety Information (continued)

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 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 box 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.

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**Hizentra®**  
Immune Globulin Subcutaneous  
(Human) **20% Liquid**

**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.**

<p><b>Have you had a lapse in your insurance coverage?</b></p> 	<p><b>Are you unable to afford your therapy?</b></p> <p>The Patient Assistance Program™</p>	<p><b>Would you like to connect with other Hizentra patients?</b></p> <p>Voice2Voice®</p>	<p><b>Do you need help paying for Hizentra?</b></p> 	<p><b>Are you unable to afford Ig infusion supplies?</b></p> <p>The Ancillary Supply Program</p>
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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
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.

subcutaneous immune globulin, have programs in which fellow patients share their own experiences with their treatment, answer nonmedical questions, connect patients with resources and offer encouragement. This type of peer advocacy is more limited than the health advocate services insurance companies offer, but it is still valuable and can be used in conjunction with other advocacy services. Some drug manufacturers such as Baxalta also offer nurse advocacy programs for insurance questions, treatment-related questions and educational resources.<sup>10,11</sup>

### How to Choose a Professional Advocate

Torrey lays out the basic framework for evaluating a patient advocate and advises starting with an interview. “It will be important to you to develop a rapport with your chosen advocate to have confidence in her abilities, to trust her to collaborate with others involved in your care and help you understand your options,” she says. “As you ask these questions, you’ll be able to tell whether she fits your needs.”<sup>6</sup>

Patients should also find out if the advocate candidates have worked with similar cases. They should ask about their credentials, and find out what services they offer to determine if those services are what they’re looking for. They should discuss the time frame and workload, and make sure those are a good match as well. What patients don’t want is to be surprised by any unanticipated charges, so the advocate’s compensation should be discussed, as well as whether pricing is a flat rate or variable depending on the type of work being done. Lastly, references should be checked. “This is perhaps the most important of all the interview questions,” Torrey says. “References are vital.”<sup>6</sup>

Torrey notes, however, that advocates may be reluctant to give out contact information for their clients because of privacy concerns. “If so, ask [the advocate] to provide your name and contact information to other patients who would be willing to speak to her abilities,” Torrey suggests.<sup>6</sup>

Researching patient advocates might sound almost as daunting as managing healthcare issues. After all, patients want to work with an advocate so they can do less footwork, not more. Therefore, patients should think of the research and selection process as putting in time up front that will be paid back to them with interest as they move through their medical journey. The payoff will be well worth the effort when their advocate helps them shoulder the burden they would otherwise be carrying alone. ■

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

## Four Ways to Recruit and Support Lay Advocates

**1** Ask people you trust. A lay advocate may see a patient’s medical records and will be privy to personal health information. As such, patients should make sure to choose someone they trust with this information. They don’t want to overhear their advocate talking about their health issues at the water cooler or the next family reunion.

**2** Choose those with the chops for the task at hand. The advocate role should be filled as if it were a professional position. In the workplace, employers wouldn’t hire someone to handle their files if they weren’t organized. The same concept applies to advocacy work. Patients shouldn’t ask someone who isn’t a good note-taker to take notes at their appointments. They also shouldn’t expect someone who doesn’t have a solid understanding of medical issues to distill their medical information. Finding the right advocate for the right type of support will make the process easier and more fruitful for everyone involved.

**3** Divvy up the work. Too much weight should not be placed on any person’s shoulders. Studies show that family caregivers can suffer from the effects of stress related to supporting their loved ones. The same holds true for those playing the role of advocate. If possible, the responsibility should be spread out among several people. Maybe a family member can go to doctor visits, while a friend can help the patient prepare for appointments. Also, areas of specialty that different advocates can focus on should be considered. This will keep advocates from getting burned out and will help ensure they aren’t stepping on each other’s toes — or the patient’s, for that matter!

**4** Remember to say thank you. Advocates are taking time out of their day (sometimes day after day) to help patients with their health and recovery. They should be told on a regular basis how much their support means. A heartfelt thank you or a personalized card can go a long way in showing appreciation.

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