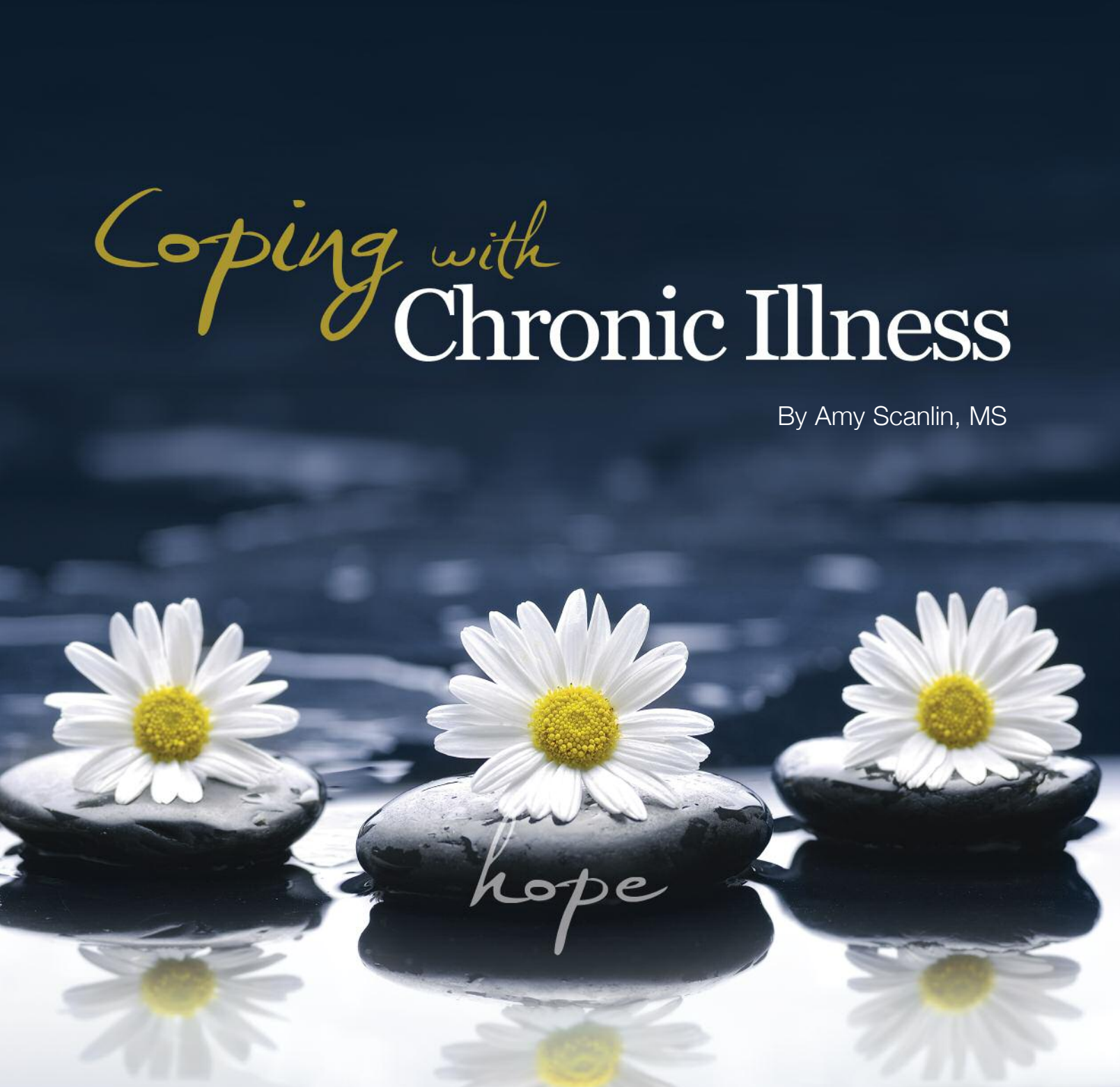
Coping with Chronic Illness

By Amy Scanlin, MS



The psychological needs of chronically ill adult patients include taking a positive outlook about their disease, learning how to control anxiety and feelings of helplessness, understanding the disease's impact on family, and establishing good communication.

Chronic conditions affect more than 162 million people in the U.S. each year, and they are the main cause of death and disability, with economic costs topping $1.3 trillion in 2003.[1] In addition to the health and financial tolls that chronic illness imposes on patients and their families, the psychological costs are astronomical. And, while great strides have been made in understanding and treating many chronic conditions, the emotional impacts are less well understood.

The uncertainty of chronic illness, including how and when it will manifest, poses one of the biggest coping challenges for patients. Patients often grapple with how they will live with the emotional stress of their condition, what type of support they will need from their families, and what types of concessions they will need from their employers and how that need will affect relationships within the workplace. "Dealing with disabilities or chronic illness is a very complicated process," explains Matthew Purinton, MSW, LSW, staff therapist for the Council for Relationships. "It's what's known as ambiguous loss, because society does not have a ritual for the loss of function or health in the same way that it does when a person dies. Therefore, dealing with this loss and finding positive ways to cope are made more difficult by a lack of a pre-existing path or ritual for coping with the loss."

For a mental health professional, the goal of helping patients manage their chronic conditions, as well as the emotional and social implications, requires a well-rounded approach. This includes helping patients understand the influences and effects of their chosen behaviors on their own health and that of their families. "The most difficult thing is the idea that the chronic illness will last for the rest of their life," explains Purinton. "Usually a chronic illness doesn't have a known end point. Instead, the person is told that they will always have to deal with the symptoms of the illness for the rest of their life. It's also difficult to see how an individual's chronic illness affects the lives of the people they love. A chronic illness isn't a static experience; instead, it ebbs and flows, with periods of greater symptom expression — good days and bad days. These bad days often will impact the person's personality, making them angry at others or shortening their fuse. The difficult thing is learning how to deal with their illness without unjustly taking it out on the people who are trying to help them."

Making Sense of Life Beyond the Diagnosis

Helping patients realize that while they may not have control over their chronic illness, they do have control over the way they choose to view that illness, as well as control over their behaviors that can both negatively and positively impact their condition. This realization is crucial to long-term success. A response shift, defined as a change in internal values, is often needed in those with chronic illness. Therefore, a valuable tool for mental health professionals helping chronically ill patients is facilitating a subsequent transformation of learning and then a changing of belief systems, feelings and knowledge that reflects the new norms and values for patients about their condition, prognosis and their role in achieving long-term success.[2]

The uncertainty of chronic illness, including how and when it will manifest, poses one of the biggest coping challenges for patients.

Says Purinton: "When the person with a chronic illness believes that there are things that they can do to improve their situation, they're much less likely to develop learned helplessness. For example, for people with chronic pain, the intensity level of the pain and the level of distrust that it causes in the person's life is poorly correlated. This means that a person with the pain level of 4 out of 10, which is considered to be significant in needing treatment, may not be able to work, while someone with an 8 out of 10 is able to. The difference often comes down to whether they believe they are in control of their life."

Patients who display resilience after a diagnosis tend to have three major commonalities: memory, hope and meaning, with memory being the link between hope and meaning. Professionals can help patients develop skills that allow them to view their illness as part of life and a challenge worth facing — far healthier than viewing their illness as a debilitating diagnosis that will soon take over their lives.[3]

A study that looked at psychological adjustments to chronic illness, published in *The Lancet*, identified four

specific factors that help patients have a healthier adjustment to their condition: physical activity, as much as is reasonably possible; finding a healthy way to express emotions; taking initiative in the self-management of their condition; and finding the positive with regard to their condition. All of these will provide the best chances for patients to experience a successful adjustment to their current and future challenges.[4]

Anxiety and Feelings of Hopelessness

Many challenges lie ahead for patients with a chronic illness, and the inability to face these challenges head-on can lead to anxiety, feelings of helplessness and depression. Even those with the best self-care techniques can be struck with periods of feeling blue and deep depression. Recognizing these symptoms early and seeking professional help can make all the difference. "Anxiety cannot be made manageable when families think of it in terms of 'for the rest of their lives,'" says Purinton. "When considering the chronic illness in its entirety, it can be especially overwhelming. By taking one day at a time, the person with a chronic illness and the family are better able to mobilize their coping resources."

Patients should be encouraged to seek counseling, even on a short-term basis, because the ability to anticipate what feelings are coming and how to best manage both the emotions and physical stress can help patients enormously. The highest risk of depressive symptoms occurs within the first two years following diagnosis.[5] Once depression starts, other behaviors come into play that can further set patients back, such as the elimination of exercise, the addition of poor eating habits and even becoming less inclined to take medication.

"Dealing with a chronic illness changes as each individual and the family progress in their development, and the family as a whole progresses through the family life cycle," says Purinton. "As a therapist, I often help families to anticipate what challenges the next stage of life will bring, as well as help them to transition and mobilize different coping resources as the needs and the circumstances change."

Impact on Families

Families of patients with chronic illness are an important concern. Though patients may feel alone in their condition, they are not. Families feel the same uncertainty over the future and how the illness will impact their relationship, their financial future, the spouse's evolving role as a care-

taker and more. Finding successful stress-management and coping skills for families is crucial to the overall success for patients and their relationships. Explains Purinton: "As a profession, social work believes that the social environment that the person finds themselves in plays a large role in their symptoms. In this context, a chronic illness is a very stressful environmental stimuli that the family must adapt to."

Families need an action plan, just as patients do, and this action plan must take into account where each member of the family is emotionally, not only relating to the illness itself but with the patients. "I look at how the family has done with periods of adversity in the past — how other members of the family have dealt with negative circumstances even if they're not a chronic illness — to help determine the resiliency of the family system," explains Purinton. "I'm also looking for other vulnerabilities that would make coping with a chronic illness more difficult: for example, economic difficulties, being victimized by prejudice, and a lack of social support. I'm looking for views that family members may have about chronic illness. Sometimes people have difficulty with the stigma of having a chronic illness. When each member of the family has a proactive coping posture, they're much more resilient against the many challenges that chronic illness often brings with it."

If you are a Hizentra patient or caregiver

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Janet Jacob

Voice2Voice is a peer-to-peer support program from CSL Behring, the maker of Hizentra.

Voice2Voice connects Hizentra patients and caregivers with advocates* who have direct experience with Hizentra and know what it's like to live with primary immunodeficiency disease (PIDD).

Go online and view stories from patients like Jacob and his mother, Janet, a Voice2Voice advocate, to see what it's all about!

Sign up for Voice2Voice.

You can enroll online at Hizentra.com/V2V or call **1-877-355-IGIQ (4447)** for assistance.

Hizentra.com/V2V

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

Important Safety Information

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

Hizentra should not be used if you have had serious negative reactions to immune globulin (Ig) preparations or a deficiency of an Ig known as IgA. Because Hizentra contains the amino acid proline as stabilizer, patients with hyperprolinemia (too much proline in the blood) should not take Hizentra.

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.

Please see additional Important Safety Information on next page.
Please see brief summary of full prescribing information for Hizentra on adjacent pages.

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

For people with PIDD

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- Hizentra helps keep IgG levels stable with low-volume self-infusions
  - —The first and only 20% Ig concentration delivers a consistent level of protection against infection
  - —Individualized dosing means you can have confidence that you are getting the dose that's right for you

Important Safety Information (continued)

Tell your doctor about any side effects that concern you. Your doctor will monitor for potentially serious reactions that have been seen with Ig treatment, including thrombotic events (blood clotting); aseptic meningitis syndrome (brain swelling); osmotic nephropathy (a kidney condition); hemolysis (a blood problem) and transfusion-related acute lung injury.

The most common drug-related adverse reactions in the clinical trial for Hizentra were injection-site reactions (swelling, pain, redness, heat or itching); 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.

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

Please see brief summary of full prescribing information for Hizentra on adjacent pages.

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

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

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Hizentra®
Immune Globulin Subcutaneous (Human) 20% Liquid

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BRIEF SUMMARY OF PRESCRIBING INFORMATION

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

Before prescribing, please consult full prescribing information, a brief summary of which follows. Some text and references refer to full prescribing information.

1 INDICATIONS AND USAGE

Hizentra is an Immune Globulin Subcutaneous (Human) (IGSC), 20% Liquid indicated as replacement therapy for primary humoral immunodeficiency (PI) in adults and pediatric patients 2 years of age and older. This includes, but is not limited to, the humoral immune defect in congenital agammaglobulinemia, common variable immunodeficiency, X-linked agammaglobulinemia, Wiskott-Aldrich syndrome, and severe combined immunodeficiencies.

4 CONTRAINDICATIONS

Hizentra is contraindicated in patients who have had an anaphylactic or severe systemic reaction to the administration of human immune globulin or to components of Hizentra, such as polysorbate 80.

Hizentra is contraindicated in patients with hyperprolinemia because it contains the stabilizer L-proline (*see Description [11]*).

Hizentra is contraindicated in IgA-deficient patients with antibodies against IgA and a history of hypersensitivity (*see Description [11]*).

5 WARNINGS AND PRECAUTIONS

5.1 Hypersensitivity

Severe hypersensitivity reactions may occur to human immune globulin or components of Hizentra, such as polysorbate 80. In case of hypersensitivity, discontinue the Hizentra infusion immediately and institute appropriate treatment.

Individuals with IgA deficiency can develop anti-IgA antibodies and anaphylactic reactions (including anaphylaxis and shock) after administration of blood components containing IgA. Patients with known antibodies to IgA may have a greater risk of developing potentially severe hypersensitivity and anaphylactic reactions with administration of Hizentra. Hizentra contains ≤50 mcg/mL IgA (*see Description [11]*).

5.2 Thrombotic Events

Thrombotic events have been reported with the use of immune globulin products[1-3], including Hizentra. Patients at increased risk may include those with a history of atherosclerosis, multiple cardiovascular risk factors, advanced age, impaired cardiac output, hypercoagulable disorders, prolonged periods of immobilization, Factor V Leiden, known or suspected hyperviscosity, and/or those who use estrogen-containing products. Because of the potentially increased risk of thrombosis, 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. For patients judged to be at risk of developing thrombotic events, administer Hizentra at the minimum rate practicable.

5.3 Aseptic Meningitis Syndrome (AMS)

AMS has been reported with use of IGIV[4] or IGSC. The syndrome usually begins within several hours to 2 days following immune globulin treatment. 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 show pleocytosis up to several thousand cells per cubic millimeter, predominantly from the granulocytic series, and elevated protein levels up to several hundred mg/dL. AMS may occur more frequently in association with high doses (≥2 g/kg) and/or rapid infusion of immune globulin product.

Patients exhibiting such signs and symptoms should receive a thorough neurological examination, including CSF studies, to rule out other causes of meningitis. Discontinuation of immune globulin treatment has resulted in remission of AMS within several days without sequelae.

5.4 Reactions Reported to Occur With IGIV Treatment

The following reactions have been reported to occur with IGIV treatment and may occur with IGSC treatment.

Renal Dysfunction/Failure

Renal dysfunction/failure, osmotic nephropathy, and death may occur with use of human immune globulin products. Ensure that patients are not volume depleted and assess renal function, including measurement of blood urea nitrogen (BUN) and serum creatinine, before the initial infusion of Hizentra and at appropriate intervals thereafter.

Periodic monitoring of renal function and urine output is particularly important in patients judged to have a potential increased risk of developing acute renal failure.[5] If renal function deteriorates, consider discontinuing Hizentra. For patients judged to be at risk of developing renal dysfunction because of pre-existing renal insufficiency or predisposition to acute renal failure (such as those with diabetes mellitus or hypovolemia, those who are overweight or use concomitant nephrotoxic medicinal products, or those who are over 65 years of age), administer Hizentra at the minimum rate practicable.

Hemolysis

Hizentra can contain blood group antibodies that may act as hemolysins and induce *in vivo* coating of red blood cells (RBCs) with immunoglobulin, causing a positive direct antiglobulin (Coombs') test result and hemolysis.[6-8] Delayed hemolytic anemia can develop subsequent to immune globulin therapy due to enhanced RBC sequestration, and acute hemolysis, consistent with intravascular hemolysis, has been reported.[9]

Monitor recipients of Hizentra for clinical signs and symptoms of hemolysis. If these are present after a Hizentra infusion, perform appropriate confirmatory laboratory testing. If transfusion is indicated for patients who develop hemolysis with clinically compromising anemia after receiving Hizentra, perform adequate cross-matching to avoid exacerbating on-going hemolysis.

Transfusion-Related Acute Lung Injury (TRALI)

Noncardiogenic pulmonary edema may occur in patients administered human immune globulin products.[10] TRALI is characterized by severe respiratory distress, pulmonary edema, hypoxemia, normal left ventricular function, and fever. Typically, it occurs within 1 to 6 hours following transfusion. Patients with TRALI may be managed using oxygen therapy with adequate ventilatory support.

Monitor Hizentra recipients for pulmonary adverse reactions. If TRALI is suspected, perform appropriate tests for the presence of anti-neutrophil antibodies in both the product and patient's serum.

5.5 Transmissible Infectious Agents

Because Hizentra is made from human plasma, it may carry a risk of transmitting infectious agents (e.g., viruses, and theoretically, the Creutzfeldt-Jakob disease [CJD] agent). The risk of infectious agent transmission has been reduced by screening plasma donors for prior exposure to certain viruses, testing for the presence of certain current virus infections, and including virus inactivation/removal steps in the manufacturing process for Hizentra.

Report all infections thought to be possibly transmitted by Hizentra to CSL Behring Pharmacovigilance at 1-866-915-6958.

5.6 Laboratory Tests

Various passively transferred antibodies in immunoglobulin preparations may lead to misinterpretation of the results of serological testing.

6 ADVERSE REACTIONS

The most common adverse reactions (ARs), observed in ≥5% of study subjects receiving Hizentra, were local reactions (e.g., 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.

6.1 Clinical Trials Experience

Because clinical studies are conducted under widely varying conditions, AR rates observed in clinical studies of a product cannot be directly compared to rates in the clinical studies of another product and may not reflect the rates observed in clinical practice.

US Study

The safety of Hizentra was evaluated in a clinical study in the US for 15 months (3-month wash-in/wash-out period followed by a 12-month efficacy period) in subjects with PI who had been treated previously with IGIV every 3 or 4 weeks. The safety analyses included 49 subjects in the intention-to-treat (ITT) population. The ITT population consisted of all subjects who received at least one dose of Hizentra (*see Clinical Studies [14]*).

Subjects were treated with Hizentra at weekly median doses ranging from 66 to 331 mg/kg body weight (mean: 181.4 mg/kg) during the wash-in/wash-out period and from 72 to 379 mg/kg (mean: 213.2 mg/kg) during the efficacy period. The 49 subjects received a total of 2264 weekly infusions of Hizentra.

Table 2 summarizes the most frequent adverse reactions (ARs) (experienced by at least 2 subjects) occurring during or within 72 hours after the end of an infusion. Local reactions were assessed by the investigators 15 to 45 minutes post-infusion and by the subjects 24 hours post-infusion. The investigators then evaluated the ARs arising from the subject assessments. Local reactions were the most frequent ARs observed, with injection-site reactions (e.g., swelling, redness, heat, pain, and itching at the site of injection) comprising 98% of local reactions.

Table 2: Incidence of Subjects With Adverse Reactions (ARs)* (Experienced by 2 or More Subjects) and Rate per Infusion (ITT Population), US Study

AR (≥2 Subjects)	ARs* Occurring During or Within 72 Hours of Infusion	
	Number (%) of Subjects (n=49)	Number (Rate†) of ARs (n=2264 Infusions)
Local reactions‡	49 (100)	1322 (0.584)
Other ARs:		
Headache	12 (24.5)	32 (0.014)
Diarrhea	5 (10.2)	6 (0.003)
Fatigue	4 (8.2)	4 (0.002)
Back pain	4 (8.2)	5 (0.002)
Nausea	4 (8.2)	4 (0.002)
Pain in extremity	4 (8.2)	6 (0.003)
Cough	4 (8.2)	4 (0.002)
Vomiting	3 (6.1)	3 (0.001)
Abdominal pain, upper	3 (6.1)	3 (0.001)
Migraine	3 (6.1)	4 (0.002)
Pain	3 (6.1)	4 (0.002)
Arthralgia	2 (4.1)	3 (0.001)
Contusion	2 (4.1)	3 (0.001)
Rash	2 (4.1)	3 (0.001)
Urticaria	2 (4.1)	2 (< 0.001)

* Excluding infections.
† Rate of ARs per infusion.
‡ Includes injection-site reactions as well as bruising, scabbing, pain, irritation, cysts, eczema, and nodules at the injection site.

The ratio of infusions with ARs, including local reactions, to all infusions was 1303 to 2264 (57.6%). Excluding local reactions, the corresponding ratio was 56 to 2264 (2.5%).

Table 3 summarizes injection-site reactions based on investigator assessments 15 to 45 minutes after the end of the 683 infusions administered during regularly scheduled visits (every 4 weeks).

Table 3: Investigator Assessments* of Injection-Site Reactions by Infusion, US Study

Injection-Site Reaction	Number† (Rate‡) of Reactions (n=683 Infusions§)
Edema/induration	467 (0.68)
Erythema	346 (0.51)
Local heat	108 (0.16)
Local pain	88 (0.13)
Itching	64 (0.09)

* 15 to 45 minutes after the end of infusions administered at regularly scheduled visits (every 4 weeks).
† For multiple injection sites, every site was judged, but only the site with the strongest reaction was recorded.
‡ Rate of injection-site reactions per infusion.
§ Number of infusions administered during regularly scheduled visits.

Most local reactions were either mild (93.4%) or moderate (6.3%) in intensity.

No deaths or serious ARs occurred during the study. Two subjects withdrew from the study due to ARs. One subject experienced a severe injection-site reaction one day after the third weekly infusion, and the other subject experienced moderate myositis. Both reactions were judged to be "at least possibly related" to the administration of Hizentra.

European Study

In a clinical study conducted in Europe, the safety of Hizentra was evaluated for 10 months (3-month wash-in/wash-out period followed by a 7-month efficacy period) in 51 subjects with PI who had been treated previously with IGIV every 3 or 4 weeks or with IGSC weekly.

Subjects were treated with Hizentra at weekly median doses ranging from 59 to 267 mg/kg body weight (mean: 118.8 mg/kg) during the wash-in/wash-out period and from 59 to 243 mg/kg (mean: 120.1 mg/kg) during the efficacy period. The 51 subjects received a total of 1831 infusions of Hizentra.

Table 4 summarizes the most frequent ARs (experienced by at least 2 subjects) occurring during or within 72 hours after the end of an infusion. Local reactions were assessed by the subjects between 24 and 72 hours post-infusion. The investigators then evaluated the ARs arising from the subject assessments.

Table 4: Incidence of Subjects With Adverse Reactions (ARs)* (Experienced by 2 or More Subjects) and Rate per Infusion, European Study

AR (≥2 Subjects)	ARs* Occurring During or Within 72 Hours of Infusion	
	Number (%) of Subjects (n=51)	Number (Rate†) of ARs (n=1831 Infusions)
Local reactions‡	24 (47.1)	105 (0.057)
Other ARs:		
Headache	9 (17.6)	20 (0.011)
Rash	4 (7.8)	4 (0.002)
Pruritus	4 (7.8)	13 (0.007)
Fatigue	3 (5.9)	5 (0.003)
Abdominal pain, upper	2 (3.9)	3 (0.002)
Arthralgia	2 (3.9)	2 (0.001)
Erythema	2 (3.9)	4 (0.002)
Abdominal discomfort	2 (3.9)	3 (0.002)
Back pain	2 (3.9)	2 (0.001)
Hematoma	2 (3.9)	3 (0.002)
Hypersensitivity	2 (3.9)	4 (0.002)

* Excluding infections.
† Rate of ARs per infusion.
‡ Includes infusion-related reaction; infusion-site mass; infusion/injection-site erythema, hematoma, induration, inflammation, edema, pain, pruritus, rash, reaction, swelling; injection-site extravasation, nodule; puncture-site reaction.

The proportion of subjects reporting local reactions decreased over time from approximately 20% following the first infusion to <5% by the end of the study.

Three subjects withdrew from the study due to ARs of mild to moderate intensity. One subject experienced injection-site pain and injection-site pruritus; the second subject experienced injection-site reaction, fatigue, and feeling cold; and the third subject experienced injection-site reaction and hypersensitivity. All reactions were judged by the investigator to be "at least possibly related" to the administration of Hizentra.

6.2 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.

Hizentra

The following adverse reactions have been identified during postmarketing use of Hizentra. This list does not include reactions already reported in clinical studies with Hizentra (see *Adverse Reactions [6.1]*).

- *Infusion reactions:* Allergic-anaphylactic reactions (including swollen face or tongue and pharyngeal edema), pyrexia, chills, dizziness, hypertension/changes in blood pressure, malaise.
- *Cardiovascular:* Thromboembolic events, chest discomfort (including chest pain)
- *Respiratory:* Dyspnea

General

The following adverse reactions have been reported during postmarketing use of immune globulin products[11]:

- *Infusion reactions:* Hypersensitivity (e.g., anaphylaxis), headache, diarrhea, tachycardia, fever, fatigue, dizziness, malaise, chills, flushing, urticaria or other skin reactions, wheezing or other chest discomfort, nausea, vomiting, rigors, back pain, myalgia, arthralgia, and changes in blood pressure
- *Renal:* Acute renal dysfunction/failure, osmotic nephropathy
- *Respiratory:* Apnea, Acute Respiratory Distress Syndrome (ARDS), TRALI, cyanosis, hypoxemia, pulmonary edema, dyspnea, bronchospasm
- *Cardiovascular:* Cardiac arrest, thromboembolism, vascular collapse, hypotension
- *Neurological:* Coma, loss of consciousness, seizures, tremor, aseptic meningitis syndrome
- *Integumentary:* Stevens-Johnson syndrome, epidermolysis, erythema multiforme, dermatitis (e.g., bullous dermatitis)
- *Hematologic:* Pancytopenia, leukopenia, hemolysis, positive direct antiglobulin (Coombs') test
- *Gastrointestinal:* Hepatic dysfunction, abdominal pain
- *General/Body as a Whole:* Pyrexia, rigors

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*.

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In dealing with emotions, "the patient has a right to feel angry and frustrated, but not a right to direct it at family members who are trying to help," says Purinton. "I tell them that it's a process that takes time to adjust to for both the person with a chronic illness and each member of the family. I also tell family members that it's OK to feel as though the care that the person with a chronic illness requires is a burden. And that's not the same thing as saying that the person is a burden or that the person doesn't want the family member to come along, even though it may mean that there are added challenges."

Only 50 percent of patients in developed countries follow therapies prescribed by their health professionals.

Enhancing Behavior Compliance

Only 50 percent of patients in developed countries follow therapies prescribed by their health professionals.[6] And yet, the quality of the patient-doctor relationship can be the most important factor relating to patient compliance for both psychological and physical behaviors.[7] A look at the current state of communication between chronically ill patients and their providers showed a positive correlation for patient compliance by displaying affective behavior, or simply asking patients about their feelings and responding to them in a way that is caring and understanding and provides a proactive approach for patients. It also is important that providers try to match the communication style of patients.[8]

Patients will be far more successful in managing their conditions when they feel their behaviors positively affect the outcome. Providers who relay the importance of external and internal responsibility, such as taking medications, exercising and other external factors that influence the disease, can guide patients to understand that they must take charge of these responsibilities.[9]

In some instances, patients and providers have the same concerns about the patients' condition, but an inability to effectively communicate those concerns leaves questions unanswered and both sides feeling frustrated. A collaborative care communication model allows patients and their providers to develop a protocol for the patients' health that takes into account the patients' priorities, as well as the doctors' care instructions. This model will enhance compliance for patients and, in turn, enhance health outcomes. Patients and providers can use the stages of change model to develop the steps patients need to take to participate in their own caretaking.[10]

"Good" communication, one that is understandable to patients, can enhance the end result of common goals and move patients forward in the health continuum. While physicians and patients can set those goals together, mental health professionals can assist patients in taking the next steps toward the mutually agreed-upon goals and help patients to understand their feelings, how to overcome setbacks, and how to keep their treatment a family affair with plenty of positive support and encouragement. ◪

AMY SCANLIN, *MS, is a freelance writer specializing in medical and fitness writing.*

References

1. American Psychological Association. Psychologist's Role in Treating Chronically Ill Persons. Accessed at www.apa.org/about/gr/issues/health-care/chronic.aspx.
2. Barclay-Goddard, R, King, J, Dobouloz, CJ, Schwartz, CE. Response Shift Think Tank Working Group: Building on Transformative Learning and Response Shift Theory to Investigate Health-Related Quality of Life Changes Over Time in Individuals with Chronic Health Conditions and Disability. *Archives of Physical Medicine Rehabilitation*, 2012 Feb;93(2):214-20.
3. MacLeod, JS. Making Sense of a Chronic Illness — A Therapeutic Approach. *Journal of Primary Healthcare*, 2011 Jun 1;3(2):136-41.
4. de Ridder, D, Geenen, R, Kuijer, R, van Middendorp, Henriët. Psychological Adjustment to Chronic Disease. *The Lancet*, 2008 Jul 19;372(9634): 246-255. Accessed at www.thelancet.com/journals/lancet/article/PIIS0140-6736(08)61078-8/abstract.
5. American Psychological Association. Chronic Illness. Accessed at www.apa.org/helpcenter/chronic.aspx.
6. Allen, D, Wainwright, M, Hutchinson, T. 'Non-Compliance' as Illness Management: Hemodialysis Patients' Descriptions of Adversarial Patient-Clinician Interactions. *Social Science Medicine*, 2011 Jul;73(1):129-34.
7. Levenstein, S. The Psychological Management of the Patient with Chronic Illness and His Family. *South African Medical Journal*, 1980 Mar 8;57(10):361-2.
8. Farin, E. Patient-Provider Communication in Chronic Illness: Current State of Research in Selected Areas. *Rehabilitation* (in German), 2010 Oct;49(5):277-91.
9. Auduly, A, Asplund, K, Norbergh, KD. Who's in Charge? The Role of Responsibility Attribution in Self-Management Among People with Chronic Illness. *Patient Education and Counseling*, 2010 Oct;81(1):94-100.
10. Boxer, H, Snyder, S. Five Communication Strategies to Promote Self-Management of Chronic Illness. *Family Practice Management*, 2009 Sep-Oct;16(5):12-16. Accessed at www.aafp.org/fpm/2009/0900/p12.html.